CHAPTER VI
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DISCUSSION

The findings of the statistical analyses of the data, that was collected during study period highlighted the importance of certain psychosocial problems of stroke patients and the utility of professional social work intervention in the alteration of such problems.

The efforts made in this study were to evolve suitable social work intervention programme and to assess its effectiveness in helping stroke patients and their families. In this chapter, the findings are discussed under the following five sections:

i. Evolution of Systematic Social Work Intervention Programme (SSWIP)

ii. Methodology of evaluation.

iii. Impact of social work intervention on -
   a. activities of daily living
   b. knowledge, attitude and behaviour of family members towards stroke.
   c. social burden on the families of stroke patients
   d. need satisfaction of stroke patients.

The findings of the present study were compared with the earlier findings of Indian and Western authors. In doing so I have encountered limitations due to paucity of similar research work by professional social
workers with stroke patients in the context of developing countries, particularly in India. Keeping this limitation in fore, an attempt has been made to discuss the findings in comparison with the research in allied aspects.

1. Evolution of Systematic Social Work Intervention Programme (SSWIP)

The SSWIP used in this study included the following elements:

- Stroke education at group level;
- Psychosocial rehabilitation services;
- Enrichment of patient's knowledge on stroke, its treatment and prevention;
- Counselling at group level;
- Vocational guidance;
- Environmental manipulation;
- Problem focussed family intervention;
- Sex education;
- Marital counselling;
- Community resource utilization;
- Case work services at individual level;
- Other social work services such as collateral contacts, supportive services, etc.

This package programme was evolved as a result of the experience in working with patients with neurological dysfunctions, and the findings of the preliminary study that was conducted and also based on the knowledge on social treatment modalities used in different settings.
It was observed that, following the initial insult of stroke in patients, there was frequently a network of supportive health care professionals to assist the persons as they were admitted in the hospital. Various activities such as physical therapy, occupational therapy, dietary consultations and visits by social workers occurred in the hospital campus in close proximity to the inpatient ward. It seemed likely that a new type of loss occurred when they returned home following discharge. The former life style in a comfortable safe setting i.e., hospital, no longer existed. At home, for almost every personal need, they were unable to cope due to the neurological deficits and disability. They were continuously confronted with diminished capabilities. Such problems definitely required structural and well planned psychosocial support and services, during their hospitalization and also in their after care.

Goodstein (1983) discussed the factors that contributed to the individual's response to stroke. These included the meaning of the disease to the individual, self-perception of the specific loss of function, the reaction of family and friends, the response of others within the social network, the effect on physical appearance and sexuality, the extent of loss of finances and loss of movement during acute hospitalization.
Watzlawick and Coyne (1980) emphasized on the need and importance of problem focused family treatment in helping stroke patients. Based on their positive results of using family intervention in stroke Evans et al (1988) suggested that education and counselling should be pursued routinely with families of stroke patients. Counselling was consistently more effective than education alone and resulted in patients improved adjustment in one year.

Stroker (1983) found that the stroke patients' families as a group was a positive force in the rehabilitation of the patients and their families towards more independent and satisfying adjustment. He emphasised the need to include the family in the rehabilitation process and said that community support of these families was also important. Singler (1983) elaborated on the purpose and methodology of group work with hospitalized stroke patients. The stroke patients discussed their fears and anxieties and shared the experiences both in and out of the hospital. The guided group interaction had immense, educational, therapeutic and rehabilitational potentials.

As observed in the above mentioned studies, based on available knowledge, training, experience and guidance and depending on the problems and situations of the patients, individualized services were appropriately incorporated into the systematic social work intervention programme.
2) Methodology of Evaluation

The method used in this study to evaluate the efficacy of the psychiatric social work intervention, involved two groups of patients: One with the routine clinical intervention and the systematic social work intervention programme and another with routine clinical intervention alone. The assessments were made at three levels—initial phase before the intervention, after six months after initiation of intervention programme and the third and final assessment after the completion of one year of intervention.

On reviewing the literature on rehabilitation of stroke, Dombovy et al., (1986) felt that if the problems related to rehabilitation were to be solved, studies must be designed to include the following criteria:

i. Strict definitions and characteristics of specific populations, sample groups and controls.

ii. Information concerning timing, duration, quantity and type of therapy.

iii. Uniform assessment of patients with measures that have proven validity and reliability.

iv. Adequate number of comparable patients and controls.

Lavenhar (1977) listed some of the major difficulties encountered in treatment outcome evaluation. They were:

i. limited generalizability of evaluative findings.
ii. lack of agreement on aims and objectives and criteria for effectiveness of treatment.

iii. inability of appropriate outcome measures.

iv. difficulties in obtaining objective and reliable measured data.

v. practical difficulties in applying experimental designs.

vi. practical difficulties in patient follow up.

To rectify these, Lavenhar (1977) formulated certain guidelines for programme evaluation. Some of the guidelines were as follows:

i. Evaluation mechanisms should be built into programmes at their inception and systematic data collection should be conceived as an integral part of the programme routine without imposing an unreasonable burden on the programme staff.

ii. Any evaluation effort should start with an explicit statement of realistic programme objectives and of the criteria for effectiveness.

iii. A variety of criteria should be considered for assessing the efficacy of a programme.

iv. Evaluation of treatment efficacy should be based on measurement of criteria before and after programme exposure and should be of sufficiently long duration to permit the assessment of long-range effects.
v. Evaluation research should be objective and based upon sound and well-considered experimentation. If a true experimental design was not feasible, then some level of acceptable control could still be achieved through quasi-experimental designs.

vi. All instruments, tests, and procedures used in the collection of evaluation data should be valid, reliable, and objective.

vii. The internal validity of the evaluative findings should always take precedence over the external validity or generalizability of the results.

viii. Evaluations should focus upon the impact of specific components of the programme as well as the impact of the total programme.

ix. Evaluation should be viewed as a continuous, circular process providing timely and useful feedback to programme administrators and staff.

The evaluative method adopted in the present study adequately incorporates the guidelines formulated by the earlier researchers and avoided certain pitfalls experienced in previous studies. The control group selected for this purpose was not deprived of any treatment, specially considering the ethical nature. As a result a model arose with two groups - one receiving routine clinical treatment and another group receiving social work intervention in
In the present study, the impact of the psycho-social intervention was assessed through these activities of daily living, family members' attitude towards stroke, burden experienced by the family and their need satisfaction.

a) Level of activities of daily living

The group of patients who had the benefit of social work intervention showed a steady improvement in their activities of daily living compared to their counterparts. Though the psycho-social measures could not influence the physical and biological abilities of the patients directly, they had enhanced the process indirectly. A patient who knew about the problem and its implications was motivated to adhere to medical advice. Similarly, when the family members were educated and counselled about the causes of stroke, prevention strategies and the importance of follow-up, their interest and involvement in the patient's progress got reinforced. As and when required, these patients were offered other appropriate personal, family and welfare services. The cumulative effect of these services had resulted in the improvement of the activities of daily living of the stroke patients studied.

Ahlsio et al., (1984) concentrated on the quality of life of patients after stroke and how this was influenced by disablement and emotional factors. They observed that among the survivors, 76% were independent as regards to activities
of daily life (ADL). Age, as well as initial functions were prognostically important factors. The deterioration was more pronounced in those patients who were dependent on others for ADL, than among those who were independent. These findings emphasised the important role of psychological support in post stroke management.

In the current study, among other improvements, ADL was significantly better in the intensive treatment group. The gain in ADL and motor function was greatest during the first six months after stroke in the intensive treatment group.

The findings of Feigenson et al., (1979) also emphasised the need for such a specialised and focussed intervention for stroke patients in a rehabilitation centre specializing in treating functional disabilities. Patients with stroke were more likely to improve if placed on a specific disability oriented unit than on mixed disability units, which were throughout the hospital.

Based on the experience, Passarella and Gee (1987) firmly believed that Bobath (1978) approach - a treatment approach based on the belief that stroke patients have the potential to regain movement and function of the affected side - could go a long way toward improving the patients appearance, function, attitude and level of independence. It could help reduce family's burden. Also, it could help prevent disfiguring contractures, progressive neglect, dwindling self-esteem and loss of abilities.
In Indian setting, Abraham (1976) enunciated that occupational therapy should incorporate indigenous ways of training and include components like use of public transport and utilities to improve ADL in a cost-effective way.

b) Knowledge, attitude and behaviour of family members towards stroke.

For proper treatment, care and follow-up of stroke patients, it was essential that the family members were adequately educated about various aspects of the illness and its implications. The efforts at educating the family members needed to be adequately monitored.

To understand the family's knowledge attitude and behaviour towards stroke, seven domains were taken into consideration for evaluation. Out of 34 items that these domains covered, nine items (1, 2, 3, 4, 5, 6, 7, 8 and 9) dealt with brain activities, causation of stroke was the focus of four items (10, 11, 12 and 13), and seven items (14, 15, 16, 17, 18, 19 and 20) highlighted the treatment processes. The risk factors and relapse were dealt with, in four items (21, 22, 23 and 24), and a set of four items (25, 26, 27 and 28) focussed on the expectations about patient's future. The occurrence and prevention of stroke were the subject matter for three items (29, 30 and 31), and the interpersonal impact of stroke was included in the other three items (32, 33 & 34).
Among these, except ten items, all other items showed significant changes as a result of SSWIP in the intervention group (IG).

Since most of the family members had the knowledge to relate the functions of memory, speech, language development and human behaviour to brain activities during the initial stage itself, the educational inputs of SSWIP could not bring a significant change in the subsequent stages of assessments.

As far as the causation of stroke was concerned, the initial response of family members was almost similar to the findings of Abraham (1976), in that 2/3 were ignorant of the causation of stroke. The commonest cause given by the families was that stroke was due to some nerve defect, and the second most common cause was blood defects. Many attributed it to 'God's Curse' and 'witchcrafts'. A significant number of respondents felt that it was due to excessive sexual involvement. In the present study the IG improved better with the SSWIP inputs. The difference between IG and NIG was significant in all the four items regarding causation of stroke.

Out of the seven items that dealt with treatment aspects, the responses to three items were favourable and positive. They were on the importance of nursing care, regularity in prescribed exercises and patients getting
engaged in some useful activities. The other items were regarding their belief in traditional healing, and hospital management. The families' responses conveyed negative attitudes and poor knowledge. The changes observed in the IG were statistically significant when compared to NIG. This finding differed from the findings of Abraham's (1976), where in he found that 70% believed modern treatment to be the best suited for stroke. Only 13% believed in native treatment. The present study accentuated that the family members' false beliefs could be changed and the convictions about hospital treatment could be strengthened by systematic social work intervention.

Risk factors play a vital role in the occurrence and in its prognosis. Solzi et al., (1983) in their study found that at least 86% of the sample presented with one or more of five etiological antecedents to stroke: hypertensive heart disease (HHD), peripheral vascular disease (PVD) diabetes mellitus (DM), myocardial infarction (MI) and atrial fibrillation (AF). Presence of hypertension significantly lowered life expectancy and so did PVD, from the earliest stages. Diabetes mellitus, the next common factor had a late influence. MI and AF contributed towards considerable decrease in life expectancy. Similar findings were reported by Kotila et al., (1984). To the knowledge of the relatives about such risk factors, there was better awareness of high blood pressure and heart disease being important factors, but
not diabetes. The family support, educational measures and other components of SSWIP influenced positive change in the knowledge on these items, as well as in their belief about the potentials of adhering to the professional advice in preventing future attacks.

With regard to the expectations of the relatives about patients’ social and job performance, it was observed that the good outcome was associated with variables like living with partner, high frequency of social contacts, previous independent living and history of ischemic attack (Henley et al., 1985). In the study conducted at Vellore by (Abraham, 1976) 80% of the respondents were in favour of reemployment of stroke patients and more than 80% had no objection towards having social contacts or marital alliance with the families of stroke patients. In the present study the IG group showed a significant improvement in respect to their beliefs regarding stroke being a life long total liability unfit for vocational activities and capability in taking up responsibilities. By altering the negative concepts, it was possible to positively influence the outcome of the patients rehabilitation.

With respect to the occurrence and presentation of stroke, the IG respondents improved significantly in all the three items related to the possibility of the illness occurring at any age with different manifestations and having
associated problems like fear and anxiety. Such knowledge broadened the motivation of the family members of the intervention group and initiated them to get involved in treatment as well as prevention of other problems, without discouragement. With reference to the impact of stroke on interpersonal relationships, the respondents did not show any significant difference between both the groups, especially in the item 'stroke causing interpersonal problems'. Stroke in one member had an impact on other family members. The reactions of these family members towards the individual with stroke also had a reverberating impact on that individual. The IG respondents were helped to experience their family's emotional support that accelerated the patients' recovery and also the need and importance of family members' cooperation. It was observed that positive behaviour of family members did reinforce patients' compliance and motivated the patients toward independent living.

The study demonstrated that systematic social work intervention programme could provide the stroke patients and their families adequate emotional support and opportunities for sharing their feelings, experiences and coping strategies within themselves and with others.

Predominantly the techniques used in the process of intervention with IG to achieve the above said awareness experiences and strategies, were clarification,
interpretation, psychoeducation, counselling, supportive and insight therapy and group interaction. Such services were provided through individual sessions, group and family sessions, both in the hospital and in the family set up. This reduced the family members' anxiety related to stroke, cleared their doubts, clarified their misconceptions and improved their understanding on the importance of their involvement in helping the stroke patients.

In a similar programme formulated by Kenrich and Robb (1988) few common themes got verbalized by families during group sessions. They were:

- Shock and disbelief about occurrence and residual deficits of the stroke.
- Signs of improvement observed and hopes for a full recovery.
- Desire to do everything possible to help the patient.
- Helplessness and powerlessness in influencing the patients' outcome.
- Concern over unpredictability and length of rehabilitation.
- Anticipated changes in roles and life style of all family members.
- Concern about stroke recurrence.

Similar observations were made in the present intervention programme. Positive developments in the family
were evident as family members verbalized an awareness of the risk factors and signs and symptoms of stroke. Several family members took initiative to reduce the risk factors in their own lives. Increased participation of these family members in the care of the stroke patients and reduction in the psychosocial problems faced by the patients and their families were the observed outcomes. The outcomes were significantly absent in NIG.

Social burden on the families of stroke patients

The social burden that the families of stroke patients underwent was assessed in seven domains. They were financial burden, disruption of family routine activities, disruption of family leisure activities, disruption of family interaction, effect on physical health of others, effect on mental health of others and subjective burden. It was observed that the efficacy of social work intervention was more in preventing the additional burden and was less in reducing the existing burden that the families experienced. Because of the stroke affecting one member, the family happened to incur financial losses and related strains. The social work intervention could not change the scene drastically. Instead, the services provided by social worker improved the situation but not to the level of statistical significance. In absence of such social work support many of the burdens increased. In fact, the increase in the
psychosocial problems experienced by NIG showed that the families of stroke patients were perpetually affected by a wide variety of problems and the problems kept multiplying if no appropriate intervention was done.

The efforts taken by the psychiatric social worker through SSWIP were geared towards bringing optimism, hope and support to the patients and to their care givers, i.e., in family members and friends. Apart from providing these, the problematic areas of their social interaction such as disturbed family structure and family patterns, difficulties with friends, troublesome neighbours and problems at work, were also intervened in order to reduce the distressing daily conflicts and to create supportive and congenial atmosphere for the patients' rehabilitation.

Four social burden aspects that showed positive and statistically significant changes in IG, following the SSWIP were:

i. loans taken, its effect on family finances, savings spent and its effect on family finances
ii. ill effect on general atmosphere of family interaction
iii. subjective perception of the family about the sufferings due to the patient's illness, and
iv. the overall mean score of all the seven domains of social burden, and the cumulative effect of all the improvements in IG, when compared with NIG.
Feigenson (1979) highlighted on the total cost for caring for a stroke patient and methods of minimising the cost. The cost could be minimized by teaching the basic principles of rehabilitation to interested friends and family members and then enlisting them in performing a range of movement activities of daily living, ambulation training and basic speech activities. He felt that by harnessing this untapped resource, rehabilitation could be started within 24 to 48 hours after admission to hospital often eliminating the added expenses of hiring extra staff to provide these services.

Lawton (1981) cautioned that environments for older people must maintain the right mix of support and challenge for each person: an environment that provides too much of support and too little challenge for well-functioning older person, might foster dependency and deterioration, although the same environment may provide too little support and too much challenge for someone who has higher needs and functions at a low level.

Stroker (1983) in his study on the impact of disability on families of stroke patients found that males scored higher than females in the areas of negative attitude towards the clients, over commitment and financial problems. The males seemed to have greater difficulty with their new roles and responsibilities as care providers. He rightly emphasised on
the involvement of the family in rehabilitation processes, and the need for community support for these families.

The systematic social work intervention programme viewed each family and the patient as an unique unit and individual respectively and significantly reduced the financial impact and improved the family atmosphere and family's confidence. It also helped families to prevent additional burdens, by strengthening them.

Need satisfaction of the stroke patients

Any psychosocially oriented intervention programme for stroke patients ought to focus on their needs too. Their needs vary from physiological needs, to security needs, need for love and belongingness, need for self esteem, and to the need for self actualization. The present study proved that the social work intervention having incorporated this aspect, was effective in meeting the different needs of the stroke patients. Similar findings were reported by Mackeen and Herman (1974). They found that the group counselling with patients of severe disability caused significant change in the level of self esteem. In case of chronic pain also, such a treatment was associated with significant increase in self-esteem (Eloten et al., 1978).

In their follow-up study of stroke patients, Robinson and Price (1982) found that almost one third of their patients were depressed at the time of the initial assessment
and two third of these depressed patients who were re-evaluated remained depressed for 7 to 8 months. The prevalence and severity of depressive disorders significantly elevated in those patients who were between 6 months and two years post-stroke. Similar levels of post-stroke depression were reported by Sinyor et al., (1986).

Binder (1984) gave specific advice and suggestions to deal with emotional problems that develop after stroke. He suggested that attention should be paid to the cognitive and emotional impairment which often would bewilder the key people; the need to relieve some patients of previous responsibilities such as paying bills, driving and working; the need for more explicit displaying of affection; the tendency of patients to withdraw from family roles despite their capacity to still perform with limitation, e.g., aphasic patient could continue to provide emotional support to others; the need for the care takers not to neglect themselves in the service of the patients; the increased tendency of stroke patients to become fatigued by activity or distracted by noise; sexual concerns and problems of the stroke patients; poor motivation which explains disability less often than depression and lack of initiative; illogic, impatience and impulsivity that could not be easily modified by rational clarifications; the need for temporary and permanent nursing home placement in some cases; and necessity of self-help group for patients as well as families.
The author also suggested that a crisis in a family could be prevented by imparting information about limitations in a hopeful manner and through brief counselling.

Wade et al (1985) suggested that the rehabilitative therapy should concentrate less on physical function and more on cognitive ability of stroke patients.

The systematic social work intervention programme, having included the above said suggestions and recommendations with socio cultural practicalities, effectively helped stroke patients and their family members to cope with their psycho-social and health needs. SSWIP also facilitated mutual help among the patients through group interactions. It improved their self help efficiency among the family members by working with the families and reintegrated the patients as individuals and as family members.

The potentials of the individual family, social network, community resources, professional and other supportive services were fully utilized for a better recovery and prevention of the recurrence of stroke.
CHAPTER VII
Stroke is a common neurological disorder. In view of its abrupt onset, considerable morbidity and as a result of motor disability, the patients with stroke and their relatives undergo significant psychosocial problems that incapacitate their personal and social functioning and effective coping to crisis. Although considerable attention has been given to medical issues related to diagnosis and treatment, no serious attempt has been made in India towards a comprehensive management, including psychosocial aspects.

An attempt has been made here to address these problems in the psycho social sphere. The state of art has been reviewed and lacunae narrated. In addition, the impact of social work intervention on the stroke patients and their families, level of activities of daily living, knowledge, attitude and behaviour of family members towards stroke, social burden on the families of stroke patients, need satisfaction of the patients, and social and vocational activities of the patients have been assessed. Based on the results of the study, modifications in patients' care in training of social work professionals, and research prospects are suggested.
The term "stroke" is synonymous with cerebrovascular accident (CVA) and is a purely clinical definition which, according to the World Health Organization, is defined as "a rapidly developed clinical sign of a focal disturbance of cerebral function of presumed vascular origin and of more than 24 hours duration".

Included within this definition are cases of cerebral infarction, cerebral haemorrhage and subarachnoid haemorrhage. Transient ischemic attacks in which recovery occurs within 24 hours are excluded. The well recognised risk factors for stroke are hypertension, diabetes mellitus, high serum cholesterol, smoking and obesity, heart disease, transient ischemic attack, oral contraceptives and increased blood viscosity. Increased stress and poor dietary patterns contribute to making one more susceptible to stroke.

The paralysis of one or more limbs and speech disturbances in some lead to serious restriction or total inability to carry out activities of daily life and the expected vocational responsibilities. Thus the patient and the family are usually confronted with drastic changes in life style. Considerable adjustment problems are bound to occur. Most of the family members get a feeling of frustration and disappointment if all the needs of the patient are not met by them. Trying to meet all the demands can be difficult, and assistance in handling some of them
becomes essential for the well being of all concerned. "Who can help?" and "Where do we go to find this help?" are questions commonly asked by the family members of stroke patients.

Review of the literature shows that although considerable work has been done on psychosocial aspects of stroke, there is paucity of information on intervention strategies to improve the patient and the family. Though professional social workers are known to make a significant contribution on the after care and rehabilitation of stroke patients, the systematised approach and research aspects have to evolve in developing countries, including India. It is essential that the psychosocial problems of stroke patients are systematically studied and appropriate social work intervention is formulated. Such an approach would enable assessment of the effectiveness of intervention programmes in tackling the psychosocial problems of stroke patients.

The idea of the present research work had its genesis in my initial training in school of social work as well as my experience in working with neurologically ill and disabled in neurological set up, at the National Institute of Mental Health and Neuro Sciences (NIMHANS), Bangalore, India.
AIM OF THE STUDY:

The study aimed to find out the psychosocial problems faced by the stroke patients and their family members, and the possible contribution that could be made by the neuropsychiatric social worker to help them in helping themselves.

OBJECTIVES OF THE STUDY:

i. To understand the family members' knowledge, attitude and behaviour about stroke illness and patients.

ii. To assess the social burden of stroke on the families.

iii. To understand the problems of the patient in regard to psychological need satisfaction.

iv. To focus on the activities of daily living of the patients.

v. To plan suitable techniques of social work intervention.

vi. To evaluate the efficacy of such social work intervention methods.

vii. To compare and contrast the group which is exposed to systematic social work intervention programme, with the group which is exposed only to the routine clinical treatment.
HYPOTHESES FORMULATED:

For the purpose of the study, the following hypotheses were formulated:

i. The group of stroke patients exposed to systematic social work intervention programme would be better in their psychological need satisfaction compared to the group not exposed to such social work services.

ii. The family members who received the social work intervention would have better understanding about stroke illness, than those who did not.

iii. The social work intervention would reduce the family burden of stroke patients comparatively better than the group which is not given social work services.

DETAILS OF PROCEDURE AND METHODS OF INVESTIGATIONS:

For the purpose of formulating social work intervention programme a preliminary attempt was made to retrospectively study 30 case files of stroke patients. On the basis of the analysis, social work programme was formulated. Subsequently patients were selected on the basis of the following criteria.

i. Inclusion criteria:

a. Patients registered at NIMHANS diagnosed as "stroke" by the consultant neurologist.

b. Hailing from Bangalore city limits.
ii. Sixty patients who fulfilled the selection criteria were included in the study.

iii. These sixty patients were equally divided into two groups: intervention group (IG) \((n_1=30)\) and non intervention group (NIG) \((n_2=30)\). This grouping was done as follows: Starting from particular date as and when a patient fulfilling the said criteria got registered, was included in either of the group, following the principle that all the patients bearing odd serial numbers to be in NIG and the even numbers in the IG. Thirty patients were included in each group.

The NIG received routine treatment offered in the hospital, whereas the IG in addition to the routine services, was given the specially prepared social work intervention package programme. Both the groups were followed up for a period of one year after being discharged from the hospital.

**SYSTEMATIC SOCIAL WORK INTERVENTION PROGRAMME (SSWIP):**

The SSWIP was organized in a manner so as to include the essential elements of professional social work which were considered necessary to cater to the needs of the stroke patients and their family members. These elements included the following:

i. Stroke education at group level.

ii. Psychosocial rehabilitation services.

iii. Enrichment of patients' knowledge on stroke treatment and prevention.
iv. Counselling at group level.

v. Vocational guidance.

vi. Environmental manipulation.

vii. Problem focussed family intervention.

viii. Sex education.

ix. Marital counselling.

x. Community resource utilization.

xi. Case work services for the patients/family members.

xii. Other social work services such as collateral contacts, supportive services etc.

For the purpose of data collection from the stroke patients and their families, the following tools and guidelines were used.

i. Interview schedule.

ii. Activities of daily living assessment proforma for stroke patients.

iii. Assessment schedule on knowledge, attitude and behaviour towards stroke.


v. Need satisfaction scale (Starck, 1984) for individuals with disability.

ASSESSMENT OF SOCIAL WORK INTERVENTION:

Information was collected at three stages. i) As soon as the patient was admitted to the hospital; ii) after a
period of six months, after being discharged from the hospital and finally iii) after a period of one year following discharge from the hospital. Generally, the second and third assessments were made in the home settings.

ANALYSES OF DATA:

The data collected through the above said tools and methods were systematically processed, classified and tabulated. The following statistical tests were used:

i. "Chi" square test of significance.

ii. Student "t" test.

iii. Step wise multiple regression analysis.

SALIENT FINDINGS:

I. BACKGROUND OF THE STROKE PATIENTS AND THEIR FAMILIES:

1. Age: In the study groups, the lowest age of the patient was 48 years, the highest being 71 years.

2. Sex: In both IG and NIG, the ratio of male to female patients was 3:2.

3. Religion: Hindus constituted 80% in NIG and 67% in NIG. The remaining were Christians (13% in IG and 27% in NIG) and Muslims (7% in each group).

4. Marital status: The majority, i.e., 73% in IG and 80% in NIG were married. Only 2 patients (7%) in IG were single and another 2 in NIG were separated.

5. Education: The illiterates constituted 13% and 7% in IG and NIG respectively. Diploma holders, graduates and
postgraduates were 40% in IG and 53% in NIG. The rest, 47% in IG and 40% in NIG had had education up to primary or secondary level.

6. Occupational Status: The occupational distribution showed that 27% in IG and 30% in NIG were housewives; 30% of IG and 23% of NIG were of Government employees; 23% were either privately employed or self employed; 13% of IG and 20% of NIG were retired; and 2/30 in IG and 1/30 in NIG were in business.

7. Family Type: The patients from nuclear families were more at IG (53%) and NIG (47%) than extended families (40% in each group). Only 7% of patients in IG and 13% in NIG were from joint families.

8. Income: Nearly half (47%) of IG and 60% of NIG members had their personal earnings ranging from Rs. 701/- to Rs. 2100/- p.m. 27% in IG and 17% in NIG, did not have any personal income as they were housewives. The rest (27% in IG and 23% in NIG) had low income, i.e., below Rs. 700/- p.m. Two thirds of the patients (70% in IG and 60% in NIG) had only one source of income and the rest had more than one source. Except 33% in IG and 23% in NIG all other patients owned lands, sites or buildings.

More than half, i.e., 56% of IG and 53% of NIG patients' families had their monthly income ranging between Rs. 3000/- and Rs. 7500/-. The rest had an income of less than Rs. 3000/- p.m.
9. **Members in the family**: For two thirds of the patients studied, in both the groups, there were four or more adult members living in their families. The remaining had two or three adults living with them. Similarly, 43% in IG and 33% in NIG had one to two children at home. 37% (IG) to 40% (NIG) had three to six children at home. The remaining had no child living with them. Thus, 77% of both the groups had five or more members living with them.

10. **Distance to NIMHANS**: About 70% of the patients in both the groups were within a distance of 10 Kms from NIMHANS. About 30% of the patients were within a distance of 11 to 20 Kms.

11. **Conveyance**: Except 10% to 20% of the families, other families had some or other vehicles - bicycles, motorcycles, scooters, four wheelers etc., as conveyance.

12. **Housing**: About 40% in IG and 27% in NIG lived in ordinary residential areas. About 13% to 17% lived in 'posh' localities. Others resided in crowded areas. Except 37% in IG and 40% of the patients in NIG, all were in rented houses. Two thirds of IG and 73% of NIG patients' houses had independent bath room and toilet facilities, and the ventilation was poor in one thirds of the houses (33% in IG and 40% in NIG).
About 60% to 70% of the houses in IG and NIG respectively had either cement or mosaic tiled flooring, while others had mud and brick flooring.

About 60% (IG) to 67% (NIG) of the houses had satisfactory water facility.

40% (IG) to 47% (NIG) of the houses, had elevated door steps, within their houses.

13. Onset of stroke illness: The onset of stroke was sudden in 47% of the IG and 60% of the NIG patients. The remaining had a gradual onset.

14. Number of attacks: For 90% of IG patients and 83% of NIG, the current attack was the first one. Others had had two or three attacks.

15. Disability: In IG 57% of the patients had right hemiplegia and 43% had suffered left hemiplegia, whereas it was 63% and 37% in NIG respectively. Four fifths of the patients in each group had mild to moderate disabilities and the rest 20% had severe level of disabilities.

16. Prehospital treatment: Majority of the patients (90% in IG and 87% in NIG) had received other systems of treatment, such as allopathy, homeopathy, ayurvedic, traditional and temple healing, before coming to NIMHANS. Only 10% of IG and 13% of NIG had not undergone such treatments. About 27% of the patients in IG and 20% in NIG had taken inpatient treatment prior to admission at NIMHANS.
17. Referral to NIMHANS: Nearly half of the patients (40% in IG and 53% in NIG) had come on their own. 30% of IG and 20% of NIG were referred by general practitioners. 20% in both the groups had come through friends or workspot. Remaining (10% in IG; 7% in NIG) were referred by traditional healers.

18. Duration of hospitalization at NIMHANS: Most of the patients (77% in IG and 57% in NIG) stayed in the hospital for less than a week. 17% from IG and 27% from NIG had stayed for two weeks and the remaining had stayed for three weeks.

19. Stroke in others: Two fifths (40%) of IG patients and 47% of NIG patients had relatives, friends, colleagues or neighbours who had stroke.

20. Source of knowledge on stroke: The initial knowledge on stroke that the patients had obtained had been from their relatives, friends and colleagues (83% in IG and 93% in NIG). Only 17% in IG and 7% in NIG had not received any knowledge from others.

II SOCIAL WORK INTERVENTION AND ITS PSYCHOSOCIAL IMPACT ON STROKE PATIENTS AND FAMILIES:

1. Impact on activities of daily living:

In regard to the activities of daily living -- like sitting in a chair and getting up from a chair, grooming, eating, drinking from a cup or glass, taking bath, dressing,
walking etc., the intervention group show far better improvement than non-intervention group, at the intervals of six months and one year.

2. IMPACT OF SOCIAL WORK INTERVENTION ON KNOWLEDGE, ATTITUDE AND BEHAVIOUR:

A. Knowledge about brain activities:

a. The IG members agreed with the statement that brain is responsible for the level of consciousness. Significant difference was found between IG and NIG during the second (p<0.05) and final (p<0.01) stages of assessment.

b. At the end of one year, more of IG patients than NIG agreed with the statement that emotions are significantly influenced by the functioning of the brain (p<0.01).

c. More IG members agreed to the statement that some problem in the brain might cause problem in thinking. At the end of 12 months the difference between IG and NIG was found to be significant (p<0.01).

d. At the end of one year, most of the family members from IG agreed to the statement that brain plays an important role in one's respiratory activities. Such a change was significant when compared to NIG (p<0.05).

e. At the end of one year 26 members in IG and 16 members in NIG agreed with the statement that functioning of the heart depends on certain aspects of the brain activities. (p<0.01).
f. In respect of the item 'the brain activities and blood pressure influence each other', the IG agreed more than NIG at six months (p<0.01) as well as one year interval (p<0.001).

B. Knowledge about causation of stroke:
   a. Less number of patients in IG believed the statement that stroke is caused by evil spirits. The difference was significant in comparison to NIG both in the six month and one year intervals (p<0.05).
   b. Assessment of second and final stage revealed a difference between IG and NIG, as less number in IG believed that the stroke is caused by previous birth, sins or karma (p<0.01).
   c. The belief that stroke is due to God's curse changed significantly in IG, during the second (p<0.01) and the final phases (p<0.001).
   d. More patients of IG understood and agreed that the patients' illness is due to disturbance of the brain, causing disability (p<0.001).

C. Attitudes and beliefs about treatment process:
   a. In respect to the common belief that by treating with special preparations like pigeon blood and other related items, one could cure stroke, more members of the IG disagreed to this significantly, both in the six months and one year follow up (p<0.01).
b. The members of IG showed increased conviction towards the hospital consultation for stroke problems at the end of one year. This was found to be statistically significant (p<0.001).
c. The belief that by visiting indigenous healers only, one could get cured of stroke weakened during the middle phase and the final phase of the study.
d. Compared to NIG, better realization of the importance of investigations for stroke patients is found in IG, at the end of six months (p<0.05) and one year (p<0.01).

D. Knowledge about risk factors for relapse:
   a. At the end of one year the IG group realized better than NIG about the fact that the present illness could be complicated by untreated diabetes (p<0.001).
b. IG members increasingly felt about the importance of professional advice in preventing further attacks. The difference between IG and NIG was statistically significant at both the stages of follow up assessment (p<0.001).

E. Family members' expectation about patients' recovery:
   a. At both levels of assessment, the families of IG patients were better than NIG as less and less in IG believed that patients with stroke invariably become total liabilities life long (p<0.001).
b. Similarly, the family members of IG patients showed significant improvement at the end of one year compared to NIG, as less of them believed that the stroke illness makes the victim totally unfit for any kind of vocational activity (p<0.001).

c. At the end of one year, more IG families developed optimism than NIG in respect of assigning responsibilities to the patient. They believed less in the statement that the patients with these problems cannot be assigned any type of responsibilities life long (p<0.001).

F. Family members' knowledge about occurrence and prevention of stroke:

a. Towards the end of six months and one year, more members in IG than in NIG understood that stroke could occur at any age (p<0.001).

b. During the period of one year, more members in IG than NIG realised that stroke can manifest in different ways (p<0.01).

c. More IG members than NIG learnt at one year that patients affected with stroke might develop fear and anxiety (p<0.001).

G. Interpersonal impact of stroke:

a. The belief in the statement that stroke in some people might lead to interpersonal problems was more
among IG members than in NIG at six months period (p<0.05).

b. At both the stages of assessment, more members in IG than NIG understood that emotional support would accelerate the recovery (p<0.01).

c. More members in IG than in NIG gained insight that family members' cooperation and support would enable faster recovery in patients (p<0.05).
H. Cumulative effect of social work intervention on knowledge, attitude and behaviour of family members:

There was statistically significant difference between IG and NIG in respect of the positive changes in their knowledge, attitude and behaviour towards stroke at the end of six months (p<0.01) and at the end of one year (p<0.001).

3. IMPACT OF SOCIAL WORK INTERVENTION ON SOCIAL BURDEN OF THE FAMILIES OF STROKE PATIENTS:

A. Financial burden:

a. In respect of loans taken, savings spent and their effect on family finances, the IG members were better than their counterparts at the end of one year (p<0.05).

b. The IG and NIG did not show any statistically significant difference in the reduction of patients's income, expenditure occurred and impact on other planned activities.

B. Disruption of family routine activities:

The items related to patients not going for work, lack of help in household work, disruption in activities on other members and other members missing meal etc showed difference between IG and NIG at both the stages of follow up assessment, but it was not statistically significant.
C. Disruption of family leisure activities:

Although there was difference between IG and NIG during the follow ups in the activities like stopping of normal recreational activities, patients' illness exhausting other's leave and leisure, patients' lack of attention to others, etc, it was not statistically significant.

D. Disruption of family interaction:

a. The ill effect on general atmosphere in the family was significantly reduced in IG than NIG at the end of one year (p<0.001)

b. In regard to the members getting into arguements, relatives and neighbours reducing the visits, seclusion of the family, etc., the change was not significantly different at both the follow ups.

E. Effect on Physical health of others:

Other members developing physical illness due to patient's condition, did not show significant change in IG and NIG during follow ups.

F. Effect on mental health of others:

In respect of any other family member losing sleep, getting depressed, crying often and related depressive futures, the IG and NIG did not show any statistical difference at the end of one year.
G. Subjective burden on the family

In the IG there was significant reduction in the subjectively experienced burden compared to NIG at the end of one year (p<0.01).

H. Cumulative effect of social work intervention on social burden on the families of stroke patients:

The cumulative effect of social work intervention was better seen in IG than in NIG after the interval of six months and one year (p<0.001).

4. IMPACT OF SOCIAL WORK INTERVENTION ON PATIENT'S NEED SATISFACTION:

a. The IG patients had better satisfaction of their physiological needs than their counterparts, at the intervals of six months and one year (p<0.001).

b. At the end of one year the satisfaction on needs on security was better in IG than NIG patients. (p<0.001).

c. The need for love and belonging were better satisfied in IG than in NIG at both the follow up assessments (p<0.001).

d. Similarly, the satisfaction of self-esteem needs was also better in IG than NIG (p<0.01).

e. The need for self-actualization was better fulfilled in IG than NIG at the interval of six months and one year (p<0.01).
f. Cumulative effect of social work intervention on patients' need satisfaction: The IG patients showed better need satisfaction than NIG at 6 months and one year intervals (p<0.01).

5. IMPACT ON SOCIAL AND VOCATIONAL ACTIVITIES OF STROKE PATIENTS:
   a. There was a significant difference between IG and NIG in respect to other services they had sought. There was decrease in their seeking of other medical, traditional, and magico-religious services, and increase in their seeking legal and welfare services (p<0.001).
   b. The work status of IG was better than NIG at both the stages of assessments (p<0.05).
   c. At the end of one year, the financial status of IG improved better than NIG (p<0.05).
   d. The continuation of personal and social activities showed better improvement in IG than in NIG at the end of one year (p<0.05).
   e. At the end of one year it was found that IG family member's expectations about patients' capacity, had more positively improved than NIG (p<0.05).
   f. The IG patients were more hopeful about their role functioning in the family than NIG (p<0.05) at the end of one year.
Applying the multiple regressive analysis, individual indicators and optimum set of indicators were identified to explain the ADL, KAB, SB and NS, in IG as well as in NIG.

Following are the major findings:

a. In the stroke patients of IG, increase in their 'overall need satisfaction' helped to improve their ADL during the first follow up period. The improved knowledge, attitude and behaviour of their families over stroke influenced the overall need satisfaction for better.

b. For NIG stroke patients, the 'number of children at home' \((r=0.531)\), the 'duration of hospital stay' \((r=0.359)\) showed positive relationship with their overall need satisfaction during first followup.

c. 'Family burden' was the only variable which significantly \((p<0.001)\) but negatively correlated with the overall need satisfaction in both IG and NIG. During the middle phase, 'overall need satisfaction', 'family burden' and 'level of disability' were the set of predictors for effective performance in their ADL in IG.

d. For NIG, 'level of disability' was the constant predictor selected to explain the patients' activities of daily living, though satisfaction of 'need for love and belonging' and the 'satisfaction of need for self-
esteem' also joined to describe their positive influence.

e. Two predictors 'overall need satisfaction' and 'family income' together explained significant positive variation over knowledge, attitude and behaviour in the IG during first followup. During the second follow up period, the 'number of children at home', along with the 'overall need satisfaction' were selected to explain 55.44% variation for the improved KAB (p<0.001).

f. Three predictors 'activities of daily living', 'level of disability' and 'duration of hospital stay' negatively explained 74.78% variation toward family burden in IG during the second assessment. The regression analysis highlighted that decrease in the number of adult members at home, in the level of ADL and in the satisfaction of patients' needs, increased the family burden significantly in IG.

g. In the non-intervention group (NIG), during the first follow up period, the 'number of adults at home' and the 'level of disability' explained significant variation over family burden. And during the final assessment the 'number of admissions' increased the family burden (p<0.001) while the 'overall need satisfaction' and the 'number of adults at home' negatively influenced the family burden.
CONCLUSION:

The present study included stroke patients in an urban setting and was conducted at a specialised apex centre exclusively for mental health and neurosciences with high quality infrastructural facilities.

The systematic social work intervention programme was developed and thirty patients with stroke underwent this programme, while another thirty stroke patients served as control group. The data collected during a period of one year clearly showed improvement in favour of the group of patients to whom the social work intervention programme was given. Significant improvement was observed in their activities of daily living, their needs satisfaction, personal and interpersonal adjustment, and vocational and social readaptation.

Furthermore, the family members of the treated group also showed favourable change in their knowledge, attitude and behaviour towards stroke as illness and the stroke patients. Their interaction and family atmosphere too improved considerably paving way for better coping pattern and effective management of their stroke patients.

If a similar study is conducted in a general hospital setting and in rural region, a more realistic picture of the psychosocial dynamics of the problems of stroke patients
would evolve, leading to improved intervention strategy, to the Indian setup.

Social intervention for a period longer than one year may be necessary for understanding the long term impact of the programme.

Future Scope:
A. Social work services:

Presently, psychiatric social work services are not adequately available in all the centres of neurological services. Many centres are totally deprived of such services. Considering the potential of professional psychiatric social workers in handling the psychosocial problems in general and neurological problems, such as stroke in particular, it is necessary to include professionally trained psychiatric social workers as neuropsychiatric social work members in the neurological team.

The neuropsychiatric social workers could get involved in social treatment, rehabilitation and after care services, and preventive educational programmes.

Attempts could be made by the neuropsychiatric social workers in neurological units to enlist the involvement, participation and support of the families and community.
B. Social work training:

Professional Social Workers are in vital positions to identify and treat the psychosocial problems of stroke patients. Unless they are experienced or receive special training in working with stroke patients, they are not prepared to work with this population. As far as professional social work training in graduate and post graduate levels are concerned, except few institutions, all the schools of social work give less disproportionately emphasis on social work in neurological setting. Rarely the field work placement includes neurological departments. Social work being a profession that enhances the rehabilitation potentials, plays a crucial role in helping the stroke patients to help themselves.

As is done at NIMHANS, special papers need to be included to cover social work with stroke patients. Adequate coverage need to be given to this important area of service. No doubt the social workers and their clients would reap the benefits of this trend.

C. Research issues:

1. The package of services which is utilized in the present study could be tried out in a variety of neurological service settings so that its utility as well as applicability could be assessed.
2. Long term follow up studies need to be undertaken to assess the different issues related to psychosocial problems of stroke patients.

3. Similar studies could be undertaken in rural areas, so that appropriate models for the majority of Indian population could be evolved.

4. The cost effectiveness of psycho-social intervention in the rehabilitation of the stroke patients could also be evaluated.

5. It is necessary to compare different group of stroke patients on the basis of the treatment. For example the following groups could be considered.
   a. Stroke patients who are on regular medical treatment.
   b. Stroke patients who are on irregular medical treatment.
   c. Stroke patients who did not received any medical treatment.
   d. Stroke patients on regular medical treatment and social work intervention.

Studies directed at answering the above issues and conducted in the community setting would be valuable in understanding the problem of stroke from psychosocial and rehabilitation point of view.
These suggestions related to service, training and research, if implemented, would definitely improve the quality of life of stroke patients and their families. The social work methods not only could effectively handle many of the psychosocial problems of stroke illness but also could prevent deterioration, relapses and hardships of stroke patients and improve/promote the coping patterns of family members living with patients with stroke.