

THE IMPACT OF CARING FOR ADULT MENTALLY ILL
RELATIVES ON CARE GIVERS IN BAHRAIN

BY

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ABSTRACT OF THE THESIS

**The Impact of Caring for Adult Mentally Ill
Relatives on Care Givers in Bahrain**

by

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The literature on care givers of the mentally ill indicate high amounts of objective burden and distress in these care givers. However, most of these studies were carried out in western cultures. The purpose of this study, therefore, was to examine objective and subjective burden in care givers of Bahraini mentally ill adult patients: patients who recently had been admitted to the psychiatric hospital in-patient facility and those who were visited by the community psychiatric team. The study also assessed some aspects of social support received or sought by these care givers as well as the relationship between this support and the level of burden experienced, using the stress-buffering hypothesis.

The convenience sample consisted of 23 Bahraini care givers: 10 selected from the community setting and 13 from the inpatient setting. The data were collected by means of in-person interviews with the care givers which were conducted by the author using a semi-structured interview schedule. This schedule is a modified version of the Social and Behavioral Assessment Schedule (SBAS) which was designed by Platt and his associates (1981). The original SBAS has well established reliability and sensitivity. The modified schedule consists of six sections addressing aspects of the patient's illness, care giver's burden and social support.

The findings of the study have replicated many of the findings of previous studies. Measures of objective and subjective burden were found to be significantly higher in the community group of care givers especially females who have longer contact hours with chronically ill patients. However, care giver's distress due to the patient's behavioral disturbance was significantly higher in the inpatient group. Aspects of social support were also found to be related differently to various aspects of burden.

The implications for research and practice are discussed. Recommendations are made for the study to be replicated with a larger sample of care givers using a longitudinal design and highly reliable measures of psychological distress.

CHAPTER I

INTRODUCTION

In many parts of the world, care of the mentally ill has undergone major changes over the last few decades. The movement away from custodial care and toward community care for the mentally ill was initiated in the United States after the second world war (Goldman, 1982). Eventually other developed countries such as Britain and Canada made significant moves in this direction. This change has placed new demands on families of the mentally ill and increased their responsibility to care for their ill members.

The effectiveness of community care in developed countries, however, is still widely debated among mental health professionals. While many advocate it in terms of cost effectiveness, others view it as a cause of hardship and burden for the families of the mentally ill, especially in the absence of adequate community support services. It has also raised doubts as to whether the mental health system is solving one problem by creating another in terms of physical and psychological adverse effects on family care givers. Lefley (1989) described the role of families as the major care givers of de-institutionalized mentally ill as an "undesired social role". She further asserts that this role has the potential for creating an at risk population of

aging parents, young children and other relatives whose mental health may be endangered by the constant stress of the patients' psychosis (Lefley, 1989).

Over the last decade, with the advent of primary health care in most of the developing countries, nursing service delivery has been shifting to outpatient community care. This shift has resulted in many nurses having direct contact with family-care givers. At present this care is focused, to a great extent, on mothers, infants, and young children, leaving much room for improvement in the care of the elderly and of the mentally disabled. The policy of community care of the mentally ill, although strongly advocated, is still in its early stages. Medication and other types of physical treatment seem to take precedence in many of these countries over psychosocial rehabilitation in the community. Therefore, a greater responsibility for the patient's care seems to fall on the family. The care givers' burden has not been studied in many of the developing countries. However, lack of research in this area is not an indication that family burden does not exist.

Traditionally in Bahrain, the family has taken responsibility for caring for sick and old members, with the female being the major care giver. In more recent years, due to such factors as the availability of long-term care institutions, the shift toward nuclear-type family, and female employment outside of the home, some families have

surrendered their care taking role to various institutions. Owing to the increase in demands on these institutions as well as various resource constraints, health and social authorities are attempting to curtail institutionalization and to reinforce the traditional model of family care.

Parallel to the above situation, there are future plans for expanding the community care services for the mentally ill. The present policy of psychiatric hospitalization in Bahrain is to discharge the non-long term inpatients back to the community as soon as their condition stabilizes. In addition, community care services which take the form of assessment and administration of maintenance medications to chronically mentally ill patients are delivered by community psychiatric teams. The patients are usually those who fail to attend the outpatient clinic for their monthly visit due to reasons such as lack of, or non-affordable transportation or problems of non-compliance.

Although the current plan in Bahrain is to work toward expansion of community care services, the first logical step in this process would be to study the needs and problems of the mentally ill and their care-givers. This seems essential in order to reduce the pitfalls encountered in haphazard adaptation of programs which have been found to be suitable for other cultures. Therefore, a need exists for a systematic study of the burden faced by families caring for mentally ill relatives in the community. Hence, the purpose

of the proposed study is to assess the nature and extent of burden experienced by family care givers of the adult mentally ill in Bahrain.

CHAPTER II

LITERATURE REVIEW

In this paper, the available literature on family and care giver burden in relation to mental illness will be reviewed. The following areas will be highlighted: social adjustment of post hospitalized patients and their families, family and care giver burden, attitudes of care givers toward mental illness, effects of various programs on the family burden, needs and perceptions of family care givers, and social support in relation to coping and care giver burden.

The amount of research on the impact of caring for mentally ill family members reflects the growing concern among mental health professionals regarding this issue beginning the mid 60's. The research has consisted primarily of clinical trials and of comparative longitudinal studies. Some studies compared community care versus hospitalization and others compared brief versus standard hospitalization in terms of the extent of family burden produced as a result of caring for a mentally ill member. The researchers have assessed the interaction between the pathological manifestations of mental illness and the social adjustment and coping of the patient and his/her family.

Some have also looked at the role of psychiatric treatment programs in influencing this interaction.

Social adjustment of post hospitalized patients and their families

Early studies focused on assessing the social adjustment of post-hospitalized patients in the community with the aim of developing suitable community programs. Mandelbrote and Folkard (1961) followed 229 schizophrenic patients, discharged from a London hospital, during a 2 year period from July 1956 to June 1958. They examined the outcome of these patients in relation to clinical and social characteristics such as inpatient/outpatient status, mental health status, effects on the family and employment status of male subjects. The patients were assessed again in the months of 1960 which provided a follow-up period ranging from 2 to 4 years. The data were collected using hospital records and case notes, interviews and the Mooney problem check list (cf. Mandelbrote & Folkard, 1961) for self rating of personal problems. They found that there were significantly more disturbed families in urban than in rural areas. Disturbance was also significantly greater in conjugal families than parental families of male patients. The opposite was found to be true for female patients. They also found high rates of unemployment among males. Unemployment was found to be associated with disturbance, but only in parental families. In a follow-up study, the

authors found that 85% of the families welcomed or accepted the patient despite the findings that 38% of these families suffered some degree of stress. Since the patients were followed for various lengths of times, and 25% of them were in hospital, these data should be interpreted cautiously. The researchers called for further research to describe the nature of the burden of those families and their need for help.

The family burden alluded to by previous researchers was described as 'tension', 'distress', and 'crisis' by Wing, Monck, Brown, & Carstairs (1964). In a study aimed at describing social and clinical progress of a group of post-hospitalized male schizophrenic patients, these researchers tested hypotheses about the association between family relationships and the course of illness. They followed 113 schizophrenic male patients, aged under 50 years, who were discharged from 8 London hospitals in 1959 following a brief hospitalization. The patients' relatives were visited before discharge, 2 weeks after discharge and at readmission. While they were out of hospital, 21 (19%) of these patients spent most of the year in lodging, while the remaining 84 (74%) spent most of the year at home. For the latter group of patients, the researchers reported that the level of tension in the family was affected by such factors as the sensitivity of the people involved, amount of physical space, toleration of neighbors and financial

status. Family's distress was related to the presence of delusions and behavioral disorders in the patient. In 45% of the 84 cases, the relatives felt distressed by the patient for at least one month before a social crisis would occur, and outside help would be called for. Of all the 113 patients, 7% were readmitted to hospital after a sudden relapse leading to social crisis. The researchers concluded that early discharge of schizophrenic patients depended on the family's willingness to accept the patient. Yet many of these families found it difficult to refuse the patient and would put up with disturbed behavior without complaint. Although the researchers did not use specific scales for quantifying the tension, distress, and social crisis, their study highlighted the conflict and stress which these families experience.

The findings of these studies reflect the universality of problems faced by the care givers when no adequate community support programs exist. Moreover, family disturbance related to patient's gender and physical space could be an issue in developing countries where strict gender roles and group type living arrangement still exist.

Family and care giver's burden

As the policy of community care continued, the issue of family burden came even more to the fore and studies became more sophisticated. The following studies examined family burden and family care giver burden as a measurable entity.

In a 4 year longitudinal study, Hoenig & Hamilton (1969), assessed the amount and type of burden which affected the patient's household. They studied 62 schizophrenic patients who were admitted to two general hospital psychiatric units from 1958 to 1959, and from 1959 to 1960. The patients and their relatives were followed and interviewed 4 years later. The sample consisted of 47% males and 53% females who were mostly chronically ill. The researchers distinguished between 'objective' and 'subjective' burden. Objective burden was defined as " a) specific effects on the life of the house hold, and b) based on the occurrence of certain abnormal behaviors in the patient which could be assumed to create stress" (cf. Platt, 1985, p.389). Subjective burden was defined as "the care givers' feeling that a burden is carried in a subjective sense" (Hoenig & Hamilton, 1969).

The researchers found that 76% of the patients produced some kind of adverse effects on their household. They also found that the duration of illness during the follow-up period affected the degree of burden only if the illness exceeded 2 years. In contrast to the findings of earlier

studies (Mandelbrote & Folkard, 1961), they found that the type of household (parental versus conjugal) did not significantly correlate with successful adjustment. They also found that burden was greater among families of male and younger age groups.

Further studies which assessed the characteristics of patients and their care givers were also consistent with the above findings. Studies carried out by the National Alliance For the Mentally Ill (NAMI), (Lefley, 1987), reported that nearly 38% of the severely mentally ill adults with history of repeated hospitalizations live with their families at some point in time. Three of the NAMI studies also reported that 85% of the care givers were parents who were mostly in their 50's and 60's. The patients were found to be predominantly male (70%), and of a median age of 33. In addition, the majority were single, unemployed and had been ill for more than 10 years with 5 or more hospitalizations. However, community program studies (CPS) showed slight preponderance of female, much younger population and predominantly single. One out of three CSP clients lived with the family, and only 12% were married and lived in conjugal homes. They had low frequency of hospitalization but depended a great deal on their families and other community resources (Lefley, 1987).

Hatfield's findings (1979, 1981) also lend support to the age and gender factor in perceived care giver burden.

She studied the nature of burden in primary care givers of schizophrenic patients. She mailed questionnaires to 225 families who were members of the Schizophrenia Association of Greater Washington (SAGW) self help group. The return response consisted of 117 questionnaires from which only 89 were usable. The researcher reported that the patients were predominantly male (71%), in their twenties (55%), lived at the parents home (57%), and the majority had been ill from 1 to 9 years. The care givers were parents in the majority of cases (85%), predominantly female, white, of middle to upper middle age and of middle to upper income. The researcher found that the most frequently reported behaviors were failures in task functioning such as inability to take care of personal needs and inability to handle money or plan for the future. The families were disturbed by the intrusion of strange habits related to sleeping and eating, negligence, argumentativeness and destructiveness.

Hoenig and Hamilton (1969) also reported the subjective burden perceived by the families they studied. Subjective burden was reported by 51% of the families as 'some', while 9% reported severe burden. On the other hand, illness produced objective adverse effects in 70% of the household, with 13% describing these as 'severe'. The authors concluded that having a psychiatric patient in the home is similar, in terms of subjective burden, to caring for a physically ill person.

Hatfield (1979) reported that the effects of patients' illness on the family were very profound. These effects included disruption of marital relationships, neglect of other children, curtailment of social life, and emotional responses such as depression, anxiety, grief, and unexpressed resentment (Hatfield, 1979). She also described these families in their sense of entrapment and disorganization as resembling those caring for members with critical and chronic physical illness.

In a follow up study of a randomly selected sub-sample of 30 out of the 72 of the above care givers who agreed to be interviewed, Hatfield looked at factors which relate to effectiveness of coping in the care givers. She followed these care givers for a period of 30 months and used questionnaires, interviews and periodic reports to determine any changes in patient's and family circumstances. Three component factors related to emotional mastery, cognitive skill and need fulfillment were rated separately for each subject on a 7 point scale and were averaged to provide a single rating scale. The results indicated that there was a possible association between effective coping in the care giver and being older and better educated. She also reported that effective copers were found to have older relatives who had been ill longer (mean duration 11.7 years) and were rated at a lower level of functioning. In contrast, the least effective copers had younger relatives

who had been ill for a shorter time and were rated as better functioning (Hatfield, 1981). The highly functioning patients presented difficulties to their families. The most common complaints expressed by care givers were that patients were unmotivated, handled money poorly, dressed slovenly, and interfered with other members. Drugs and alcohol were also a problem for some of these patients (Hatfield, 1981).

Family's attitude toward the mentally ill

The willingness of families to care for burdensome mentally ill members at home has been documented in both early and recent literature (Wing et al., 1964; Doll, 1976; Goldman, 1982). With the aim of looking into family burden and adjustment to mental illness, Doll (1976) assessed significant others (parents, spouses, and other relatives) of 125 randomly selected mentally ill patients, who had been released recently from 3 state hospitals. The informants were predominantly of lower middle to lower class, had no more than high school education, had average to low incomes, and of whom 40% were black. The majority of patients had multiple admissions, 17% were severely disturbed and 44% were unemployed. The assessment consisted of an interview, a questionnaire with demographic and attitudinal items, and an incomplete sentence test (Doll, 1976) to elicit ambivalent feelings towards the ill members. The results showed that these relatives were mostly troubled by the

patient's persistent and severe psychiatric symptoms. The more severe the symptoms, the less sympathetic were the relatives, of whom 67% reported embarrassment and shame. Based on the finding that only 12% of the patients were re-hospitalized, the researcher concluded that physical tolerance of the mentally ill at home was not an indication of social acceptance (Doll, 1976). Therefore, he challenged the notion that re-hospitalization of chronic patients is an index to failure in social reintegration. While the demographic characteristics of the sample limit generalization, the results alert us to the fact that attitudes toward the mentally ill are very much influenced by the severity of their symptoms, even among their own families. The findings also implied that the reasons for re-hospitalization needed to be investigated further.

In a chart review study, Surber and his colleagues (1987) looked at factors which determine high use of psychiatric in-patient services. The charts of a sub-sample of 35 patients were reviewed from June 79 to Jan 1983. These patients were randomly selected out of 99 patients who used the services between 1980 and 1981. The researchers found that 28% of these patients were schizophrenics, 23% had a diagnosis of bipolar depression, 9% diagnosed as border line personality and 40% had mixed diagnosis. The average number of admissions of these patients to the facility was 3.5 times a year. They also found that 57% of

these patients were violent or had fear-producing behavior on admission, 29% were self destructive, 80% had difficulty in managing money and 77% had housing difficulties.

Moreover, the charts showed that families of 80% of these patients remained involved in their lives.

Effects of various programs on family burden

Some studies have attempted to measure the objective burden of families in relation to hospitalization and community care of mentally ill relatives. Over a 2 year period, Grad and Sainsbury (1968) assessed the impact of 2 types of psychiatric treatment programs on the patients' families. A control treatment program consisted of standard hospitalization, while the experimental program consisted of brief hospitalization followed by community services. The authors developed a rating scale of objective burden which contained items relating to the effect of the patient on work, leisure, income, health of the family, the children, and the family's relations with neighbors. It also assessed the amount and type of care which the family had to provide for the patient. The sample was selected at random and consisted of 271 families referred to the community support treatment program, and 139 families referred to the standard hospital treatment program. However, the follow up findings were reported about a final sample of 329 patients who were still alive at follow up and whose families were available. The closest relative was interviewed at home within 1 month

of referral, and again two years later. The effects of the services were assessed by comparing data obtained at the 2 visits.

Consistent with previous findings, they found that family burden depended on severity of clinical symptoms and duration of the illness. Family burden was not found to be related to the gender of the patient but increased with his/her age. Higher rates of readmissions were found in standard hospitalization type of service. The researchers also reported that mental health of more than 1/2 of the informants in the study was affected at the time of patients' referral, social and leisure activities were restricted in 1/3 of the families and that income had been cut off to less than 1/2 the usual level in 10% of the families. The researchers found that the difference between the 2 services was statistically significant in only 2 items: financial burden, and effects on mental health of the family care giver. However, they reported that there was a trend for all aspects of care to be adversely affected in the community support type of service. Therefore, Grad & Sainsbury (1968) concluded that community care service was higher in social cost than hospital based service. Furthermore, they emphasized the importance of supplementing the clinical care of patients treated outside the hospital with adequate social support to the family.

In a similar study, using a modified family burden scale based on Grad & Sainsbury's work, Test & Stein (1981), set out to investigate the effects of two different treatment modalities on family and community burden. They randomly assigned mentally ill patients to a 'training in the community living' experimental group and to a 'short term hospitalization plus after care' control group. The final sample consisted of 50 patients in each group, who had family members living in Dane County. Data were collected within one month of referral and at 4 months. However, families of 28 patients only in the experimental group and 21 patients in the control group were accessible for interview at the one month data collection period. The families who completed the first interviews were approached at the 4 month data collection period. The final results, therefore, were reported about 22 families in the control group and 18 in the experimental group.

The researchers found no significant differences between the two groups on the various items of burden. They concluded that the experimental community treatment program placed no more burden on families and the community than did the hospitalization approach. The researchers comment that the results reflect the vast amount of support given to patients and their families in this particular community treatment program. They also add that findings are not generalizable to situations where such support does not

exist. However, generalization of these findings is questionable due to the small number of families interviewed, and because of the lack of information on the family members who were not available for interview.

Two other clinical trials have been conducted to compare brief versus standard hospitalization in terms of their effects on the patients' families (Herz, Endicott, & Spitzer, 1976; Platt & Hirsh, 1981). In their study, Herz and associates randomly assigned 175 newly admitted patients to 3 treatment groups: 1) 'standard' group who were discharged at the psychiatrist's discretion, 2) 'brief day' group who were hospitalized and then received transitional one day care treatment, and 3) a 'brief out' group who were briefly hospitalized and then discharged to the community (Herz et al., 1976). Sixty three percent of those patients, were diagnosed as schizophrenics, 1/3 were black, more than 1/2 were of low socioeconomic status, and more than 1/2 were under 35 years of age. The number of males and females was equal in all groups. The groups were evaluated at 3 weeks and at 3, 6, 12, 18, and 24 months after admission. The instruments consisted of psychiatric status schedule, patient and family evaluation form (FEF), and a mental status examination recorded by the psychotherapist. The family evaluation form consisted of 455 items, grouped into 45 summary scales. It covered 3 major areas: Patient evaluation, Family evaluation, and Family difficulties due

to the patient. It took 45 minutes to complete. The FEF revealed no significant differences between the 3 groups on admission and at follow up evaluations. There were only 2 significant differences out of 117 measures of family difficulties at 3 weeks; the 'brief day' group scored higher on the summary scale on community problems than the 'brief out' group, and the latter group also scored higher on objective burden due to patient than did the 'standard care' group.

In a similar study, Platt & Hirsh randomly assigned 224 mentally ill patients to a 'standard care' group and a 'brief care' groups. The two groups were compared at 1 month before admission, 2 weeks after admission, and 14 weeks after admission. The patient's significant others were interviewed using a semi-structured, standardized interview schedule (PBAS), which was later modified and renamed the Social Behavior Assessment Schedule (SBAS) (Platt & Hirsh, 1981). The instrument assessed the 'adverse effects' of the patient's behavior on the care giver and his/her household (objective burden) and distress to the informant due to the patient's disturbed behavior, limited role performance and adverse effects on the household. The researchers reported no significant differences between the 2 groups on objective burden at 1 month before admission, at 2 weeks after admission and at follow up. Also, no significant difference was found between the two groups in

the area of subjective distress at neither 2-week or 14-week evaluation. The authors concluded that the findings are a close replication of those of Herz and associates (1976).

The clinical trials reviewed so far have all indicated that there is no difference between the groups studied in the amount and type of burden experienced. In a study done with Indian patients, Pai and Kapur (1981), reported significant differences between 'hospital care' and 'home care' in terms of burden. They assessed the relationship between clinical psychopathology, social dysfunction and family burden and whether there were any significant changes in this relationship as the treatment progressed. They assigned newly admitted/ newly diagnosed schizophrenic patients to the 2 above groups using a systematic random procedure. There were 27 patients in each group. Those in the 'hospital care' group were admitted and discharged at the discretion of the psychiatrist, while the 'home care' patients were visited at home by a nurse trained in counselling. The nurse's role consisted of administering medication, counseling patients and relatives, and reporting to the psychiatrist about the patient's condition. A burden scale based on the one designed by Grad & Sainsbury (1968), was used to assess 6 major areas of objective burden on the family. The assessment was done on 8 occasions throughout the 6 month period of follow up. The findings indicated

that home treatment was associated with reduced family burden. The authors concluded that care of the patient at home leads to alleviation of the family's anxiety and so lessens the burden. However, these findings should be interpreted with caution due to the effects of frequent testing on the subjects' responses, as well as the lack of information of the quality and quantity of care offered for both groups. Generally, the above clinical trials have indicated that community care programs do not place objective burden on families of the mentally ill or cause them distress any more than does hospitalization. Yet, many of these researchers emphasize the importance of providing frequent support to patients and their families, if these community programs are to have any effect on lessening the family's burden (Grad & Sainsbury, 1968, Test & Stein, 1981; Pai & Kapur, 1981). Some also call for considering the needs of the community and families when such programs are designed (Test & Stein, 1981). Although subjective burden assessment is of value in examining family care givers' distress, some of the above studies have given it little importance or omitted it completely. Methodological issues also seem to limit generalizability of some of these clinical trials.

Needs and coping of family care givers

The following studies, which dealt with the needs of the families of the mentally ill, are few in number and are

of limited generalizability. A mail survey looked at the type and extent of support available, and the perceived needs of families of schizophrenic patients (Hatfield, 1979). The researcher found that the majority of families sought help from friends, relatives and staff of the available self help group. Professional services of individual, group, and family therapy were highly used by these families, even though the families expressed low satisfaction with these services. Fifty seven percent of the respondents also expressed a greater need for information and education on symptoms, medications and patient's management techniques at home (Hatfield, 1979). A considerable percentage of the care givers (55%) expressed the need to talk to people with similar problems, people who have known the experience of caring for a mentally ill family member. Some family care givers (44%) also expressed the need for shelter for the patient and respite care (Hatfield, 1979). However, the above is a select group because they were predominantly females, white, of middle to upper middle age, middle to upper middle income, and of high education.

Similar results have been reported in studies investigating the burden of mental health professionals who have mentally ill family members, and in studies examining the burden of spouses of depressed patients (Lefley, 1987; Fadden, 1988). In a mail survey of 84 mental health

professionals , Lefley (1987), found that this sophisticated group of carers was not different than non professional families in their needs for support and information about the symptoms. Lefley found that having a mentally ill family member resulted in 72% of these professionals seeking psychotherapy. A common need expressed by this group, and by the non-professional group, was the need for separate housing arrangements for the patient (Hatfield, 1979; Lefley, 1987).

In a follow up study of primary care givers of schizophrenic patients, Hatfield (1981) looked at various factors which determine coping effectiveness of these family care givers. She reported that those who were successful in coping found outlet for their personal interests such as travel, hobbies, participation in clubs or other social activities, while the unsuccessful copers mentioned fewer and different interests (Hatfield, 1981). Effective copers also seemed to be better able to achieve a degree of acceptance of illness which reduced their stress and helped them deal constructively with every day problems. She also found that these effective copers placed more emphasis on understanding the illness and on learning about patients' behavioral management (1981).

The above studies, have highlighted some basic needs of families for information about symptoms, medication, and help with management of the patient. Higher priorities were

given to affiliation with self help groups in contrast to traditional psychotherapy. The need for residential separation from the patient was expressed constantly by these families.

Social support, and care giver's burden

Over the past few decades, the concept of social support has received tremendous attention from researchers in various fields. Social support has been viewed by many researchers as a moderator variable between stress producing situations and various physical and psychological symptoms and disorders (Barrera, 1986; Leavy, 1983; Cohen & Hoberman, 1983; Dean & Lin, 1977).

The social support phenomenon has been studied from three perspectives: network structure or social ties, functions of supportive resources, and nature of the relationship between the individual and his/her network members. Similarly, most social support instruments measure three aspects of social support relationship; existence or quantity, content or type, and quality or adequacy (Stewart, 1989). Cross sectional correlational designs have been the main research designs used in the field of social support, although a few recent studies have used a longitudinal design (Barrera, 1986).

The social support literature is consistently criticized. Many of the criticisms relate to lack of consensus on how the concept of social support is defined

and measured, vagueness in definition and specification of the concept, and lack of consistency in research findings (Barrera, 1986). In an extensive review of the concepts, measures, and models of social support, Barrera argues that social support should be defined in more specific terminology, instead of using a global definition. He asserts that the social support construct is multidimensional and that concepts which are the subject of inquiry need to be specified, and that specific measures should be selected in order to clarify confusion and resolve inconsistencies in findings (Barrera, 1986).

A review of some studies which looked at social support in relation to coping and distress outcomes in care givers lends support to the above position. That is, as will be seen in the few studies reported here, various aspects of the social support phenomenon are found to be related differently to the care giver's distress or his/her ability to cope with care giving burden. Hatfield (1979) reported on the family care givers of schizophrenic patients and their use of various social support resources. Eighty four percent of family care givers valued friends very highly, and 73% valued relatives, in contrast to 55% who chose individual therapy. This finding, the researcher explains, contradicts the frequently held assumption that families of schizophrenics are isolated or cut off (Hatfield, 1979). In

addition, those care givers were members of a self help group for schizophrenic patients and their families.

In a follow up study of the same population, Hatfield (1981) assessed the social support systems of these care givers in relation to their effectiveness of coping. She reported that effective care givers turn to friends and relatives more frequently than do the less effective copers. The less effective copers, however, value the support they receive from these resources as high or very high. The less effective copers also turned to professionals more frequently and valued their help more than the effective copers. Both groups, however, were equal in their use and valuing of the staff of the self help group to which they belonged.

Since there are few studies which address social support and coping in care givers of the adult mentally ill patients, the available literature on care givers of Alzheimer's patients will be reviewed in order to identify potentially relevant concepts and findings. The literature on social support for family care givers of the elderly Alzheimer's patients is very diversified. Social support has been studied in relation to various outcomes and sometimes yielded inconsistent findings. A study assessed the social network of spouse care givers of Alzheimer's patients as a potential source of both stress and support (Fiore, Becker, & Coppel, 1983). The sample consisted of 44

care givers to institutionalized (n=11), and non institutionalized (n=33) spouses. The care givers' ages ranged from 45 to 85 years. Five categories of social support were assessed: socializing, tangible assistance, cognitive guidance, emotional support and self disclosure. Four semi-structured interviews were administered to these subjects over the course of several sessions in addition to paper and pencil tests. The tests included 2 measures of social support, the Beck depression Inventory Scale, and a diagnosis based on the SADS-C interview (adopted from Endicott & Spitzer 1978), and the Research Diagnostic Criteria. The measures of depression were obtained two weeks after administering the social support assessment.

The researchers reported highly significant correlations between perceived upset and depression but none between perceived helpfulness and depression. Correlations were also obtained between the measures used as indices for social support i.e., frequency of contact and frequency of asking for support and a) depression, and b) perceived helpfulness and upset ratings (Fiore et al., 1983). Frequency of support correlated inversely with the depression score but not to the same level as the upset ratings. Frequency of contact also related to helpfulness experienced in the areas of socializing and tangible assistance and to a minimization of upset in the areas of emotional support and self-disclosure. An unexpected

finding was that frequency of asking for support from the network correlated positively with depression. Asking for support was also correlated significantly with helpfulness experienced in all support areas but very markedly in the areas of tangible assistance and cognitive guidance (Fiore et al., 1983). The researcher concluded that the perception of social network helpfulness did not relate to the severity of depression in this population, but that depression is related to the degree of upset experienced in any area of support as a result of negative input or unmet needs of these care givers (Fiore et al., 1983). The researchers called for longitudinal designs studies to address these issues.

Another study of family support to care givers of Alzheimer's patients (Scott, Roberto, Hutton, 1986) also reported a somewhat similar finding when it comes to the amount of support received in relation to care giver's burden. The study examined the instrumental and social-emotional support provided by other family members to 23 care givers (male= 35%, female= 65%) and its relation to perceived degree of burden and coping effectiveness of these care givers. A second family member who usually was the next closest of kin to the care giver was interviewed in order to provide another perspective of family support to the care giver. The mostly reported types of instrumental and social help received by these care givers were respite

care (52%) and advice and information. The researchers found that greater burden was perceived by care givers who reported not receiving enough support. However, care givers who rated their support as more than enough were similar to those with inadequate support in the amount of burden reported, while those receiving enough support were the least burdened. The results also indicated that care givers who received more than enough support scored better in coping effectiveness than did those who received lower amounts of support. The authors explained the relationship between burden and support to be in reverse of the causal direction of support and care giver's outcome implied in the study, i.e., The greater the risk of dysfunction in the care giver, the more support given. However, generalizability of these results may be limited due to the size of the sample.

A study by Baillie and colleagues (1988) shares similar findings to the above two studies when it comes to the effect of social support on outcome. The researchers investigated the effects of perceived care giver stress and social support on the psychological distress of family care givers of the elderly, using the stress- buffering model to test the main and interactional effects (Baillie, Norbeck, & Barnes, 1988). The subjects consisted of 87 care givers of Alzheimer's patients who provided care for the elderly either in their homes or in the elder's home. They reported that perceived stress of care giving was found to be

positively related to psychological distress and depression, and that satisfaction with social support was negatively correlated with psychological distress, and depression (Baillie et al, 1988). However, multiple regression analysis controlling for the patient's mental condition and the duration of care indicated that the relationships between the perceived stress and the outcome variables were spurious. In addition, the main effects of social support in predicting psychological distress was substantial but there was no evidence of buffering effect of social support. The authors conclude that their study replicates findings from many other studies when it comes to the main and interactional effect of social support, with a difference in the higher magnitude of the effects of social support found in this study.

Other researchers on care givers of Alzheimer's patients looked at group intervention effectiveness in reducing care givers' burden (Robinson, 1988; Toseland, Rossiter, Labrecque, 1989). In an intervention study with 20 subjects, Robinson (1989) reported a significant decrease in both objective and subjective burden in a treatment group of 11 care givers in comparison to a control group of 9 care givers. The original purpose of the intervention was to increase the care givers' self esteem and therefore increase their social support resources and decrease their burden. The intervention in the treatment group consisted of

education about the nature of disease as well as a social skill training component. However, self esteem measures did not show any significant differences at pre and post tests (Robinson, 1988). The small sample size and other confounding factors limit generalizations of these findings. In contrast, Toseland and associates (1989), reported no significant findings in relation to the effects of various group interventions on care givers' burden.

Findings of the above studies on social support and care givers' burden or their coping are shown to be inconsistent. Hatfield's findings on effectiveness of coping in care givers' of the mentally ill patients in relation to social support from formal and informal network members do not clearly indicate which aspect of social support was most helpful. Studies of care giver's of Alzheimer's patients, on the other hand, are more explicit in relating various aspects of the social support phenomenon to outcomes of burden and coping. Evidence supports the notion that social contact and satisfaction with support is related to low levels of care giver's psychological distress. Nevertheless, the results concerning the amount and type of tangible assistance received are inconsistent. That is, tangible assistance is reported to result in an increase of care givers' coping effectiveness but does not decrease their burden (Scott et al., 1987). There is also a doubt regarding the interactional effect of social support.

Summary

The available literature on the impact of mental illness on the family has highlighted important issues as well as revealed a number of theoretical and methodological gaps. The first and most apparent of these gaps is the lack of theoretical framework in most of the studies reviewed. Secondly, while the needs expressed by these families, such as the need for information about patients' management and medications, as well as supportive counseling fall very much within the domain of nursing, none of the studies were done by nurses. The study done in India, however, used a nurse's service as part of the comparative study, and the researchers concluded that a future study should look into what aspect of the nurse's work contributed to the success of the program. Clearly, the situation calls for more input from nurse researchers and practitioners to define nursing roles and responsibilities in these care-giving situations.

Some of the studies have looked only at objective aspects of family burden, a point argued by some authorities to be inadequate when the aim is to establish community care programs. However, some used the term 'subjective' to refer to the personal evaluation made by the interviewer.

There were methodological flaws in many of the studies. The use of small samples in some of the studies and lack of information on the characteristics of the defaulters, places

limitations of the generalizability of the findings. Some studies used mailed questionnaire survey designs, resulting in self-selected groups. Other studies had a very low response rate; as low as 46% (Hatfield, 1979).

Many of the researchers, with the exception of Pai & kapur (1981), have mainly investigated the impact of caring for chronically mentally ill member on the family. A few have included both newly hospitalized as well as chronically mentally ill patients in their samples. These researchers found that the longer the duration of the illness the greater was the burden. Yet, none of them looked at the recent onset of the illness as an independent variable in relation to various aspects of burden, especially those related to subjective burden.

Another aspect which has not received much attention is the effect of social support network on the way family care-givers cope with mental illness. Although Hatfield (1979; 1981) outlined the needs of family care givers for social support as well as the type of social networks utilized, the nature and the extent of help provided by these networks is not clear. It is also essential to examine the effect of the social network on individuals and families in traditional cultures where social and kinship ties are extended. This aspect has not been systematically investigated in Bahrain. It would be of interest to look at the effect of this factor on family burden especially at a

time of rapid development and cultural transition. Also related to this aspect is the attitudes of the family care givers to the patient living in the same household. Many of the early and recent studies done in western cultures have pointed to the family's need for a separate living arrangement for the patient. It would be of interest to look at how care givers in the Bahraini culture tolerate this aspect where social customs and norms strictly discourage non married family members from living separately, and where families are committed to caring for and protecting the mentally ill members.

Conceptual Framework

The conceptual framework for this study is based on findings in the literature on coping and burden of family care givers of the mentally ill patients as well as from the literature on social support in relation to various outcomes studied. The stress- buffering model of social support will be used here as a guide to understand the relationship between various aspects in the care giving situation and the role of social support in modifying their effects on the care giver. The following factors will be incorporated into the proposed stress- buffering model:

1. The patient's characteristics
2. The care giver's characteristics

3. Objective and subjective burden.
4. Perceived social support

1. The patient's characteristics

Early studies investigated community adjustment of post hospitalized and post de-institutionalized patients. Indicators of levels of community adjustment such as employment, social role functioning and rates of hospitalization or relapse were studied in relation to nature of psychiatric illnesses, severity of symptoms and demographic factors. Certain groups of mentally ill patients particularly those with schizophrenia were studied extensively especially since the nature of illness is accompanied by frequent exacerbations and remissions, which leave major long term residual effects on the patients' behavior and interferes with their community adjustment.

An early study which assessed social adjustment of post hospitalized patients in the community found that disturbance was significantly greater in conjugal families than parental families of male patients, and that the opposite was true for female patients. High rates of unemployment among males was also found to be associated with disturbance in parental families (Folkard & Mandelbrote, 1961). Another study by Wing and his associates (1964), looked at the responses of families who cared for patients in the community and who had to deal with

recurrent exacerbation of the illness. They described these responses according to their severity as 'tension', 'distress', and 'crisis'. Among other factors, family distress was related to the presence of delusions and behavioral disorders in the patient. These researchers also found that many families were willing to accept the patient at home, even if they expressed distress at his/ her behavior (Folkard & Mandelbrote, 1961; Wing et al., 1964). Professionals then began to appreciate the impact of the patients' illness and their level of adjustment on the family and began to consider them as potential stress factors.

The term 'burden' was generally used to describe the adverse effects of the patient's illness on the family care giver and his/her household. Most of those studies reported that the degree of burden was associated with the duration of illness (Hoenig & Hamilton, 1969; Lefley, 1987a). The studies also indicate that burden is greater among families of male and younger age groups. Recent studies on the nature of care giver's burden also lend some support to the above findings. These studies report that the patients are predominantly male, young single and live in the parent's home. In addition, the majority are unemployed and had been ill for more than 10 years with 5 or more hospitalizations (Lefley, 1987; Hatfield, 1979, 1981). Deficits in social

and interpersonal skills was also a feature of these patients.

2. The care giver's characteristics

In contrast to the theories on role of the families in producing the illness or leading to exacerbation or relapse, some researchers looked at the families' responses to and coping with the patients' illnesses and the deterioration in their every day social functioning. They also looked at the family's situation and attempted to identify variables relating to tolerance of the patient's illness and level of functioning. Some of the factors which were repeatedly mentioned in this regard were the type of family, i.e., conjugal versus parental, the demographic characteristics of the care giver and type of his/her relationship to the patient.

Some studies reported that the majority of the burdened care givers are parents in their 50's and 60's. Most specifically, mothers are the main care givers of young adult patients who are predominantly male, young, single and live mainly at the parents' home. Studies which looked at coping in these care givers reported that effective copers were usually older in age, of higher education, more accepting of the patient's illness and were socially active. Moreover, these care givers were usually caring for older and lower functioning patients (Hatfield, 1981). On the other hand, ineffective copers tended to be younger, less

socially active, and were more resigned toward the patient's illness. These care givers were usually caring for younger and highly functioning patients (Hatfield, 1981).

3. Objective and Subjective Burden

With the increased movement toward community care, families responsibilities for caring for their mentally ill members have also increased. Researchers then began to look at the objective cost of care giving in families of the mentally ill, especially in relation to physical and psychological ill health and socio-economic aspects. Some researchers also attempted to measure the subjective distress perceived by the family care givers due to the difficulties encountered when caring for a mentally ill relative.

Clinical trials were conducted in order to compare the community care approach to hospitalization in terms of cost effectiveness. One of the early studies found that community care was associated with higher social cost to the care giver especially in terms of physical and emotional disorders and financial burden (Grad & Sainsbury, 1968). In contrast, majority of later studies reported no significant differences between the two approaches in terms of care givers' objective burden (Test & Stein, 1980; Platt & Hirsch, 1981). Moreover, there were inconsistent reports regarding the relationship between objective burden and the patient's behavioral disturbance and his/her level of social

functioning. The aspects of subjective burden or distress of family care givers were rarely assessed in these clinical trials.

Health professionals began to be concerned, however, about psychological and physical adverse effects of caring for chronically ill family members and how these adverse effects were influenced by the social support resources available for the care giver. Patterns of coping, perceived distress, needs and perceived satisfaction or lack of it, were assessed in relation to various aspects of formal and informal support available for the care giver. Care giver's distress seem to be associated with social support received whether from formal or informal support network. Care givers seem to seek friends, relatives and members of self help groups who have similar experiences with mentally ill family members (Hatfield, 1979, 1981; Lefley, 1987b). Although some care givers seek professional therapy, the majority express dissatisfaction with the mental health system. Most of the care givers' dissatisfaction stems from lack of adequate formal support programs in the community (Lefley, 1987b; Francell, Conn & Gray, 1988).

4. Social Support

In studies of care givers, other than those caring for mentally ill relatives, various dimensions of social support were assessed in relation to different outcomes such as

burden, coping effectiveness, psychological distress and depression. The "stress-buffering hypothesis" of social support was used as a conceptual framework in many of those studies. This model was based on earlier findings in the social and epidemiological fields of the role of social support in influencing outcomes of stressful life events such as morbidity, psychological symptoms and disorders and even mortality (Dean & Lin, 1977; Leavy, 1983). This hypothesis predicts that the higher the level of social support available to a person, the more he/she is protected from stress-induced pathology (Cohen & Hoberman, 1983). On the other hand, this hypothesis also suggests that the level of social support is relatively unimportant for people experiencing low levels of stress.

Findings of studies addressing social support and care givers' burden are very inconsistent. A number of the studies reported an inverse relationship between care givers' psychological distress or depression and their perceived satisfaction with the support they receive from their network (Fiore et al., 1983; Bailie et al., 1987). In contrast the amount of tangible help received from network members seemed to have a positive relationship to care giver's depression and his/her amount of burden. This supports the opinion of some authorities that social support phenomena is multi-dimensional, and that various models may

be used to study the relationship between each of its concepts and the various outcomes (Barrera, 1983).

In this study, the patients' illness and other related factors will be regarded as stressors which interact with various aspects in the care giving situation such as care givers' characteristics. This interaction will result in objective and subjective burden which are seen here as the outcome. Using the "buffering hypothesis" discussed above, it is assumed that the care givers' burden will be lessened as a result of receiving greater social support (see figure 1).

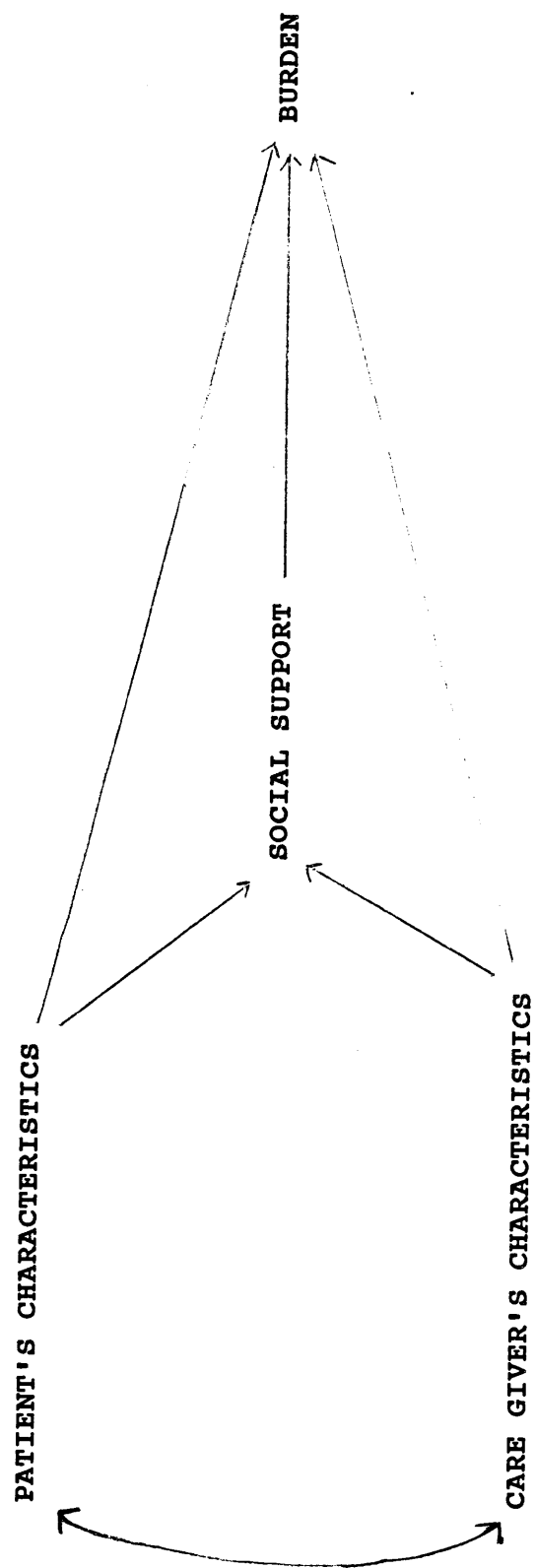


Figure 1. A conceptual model depicting the relationship among variables.

Hypotheses

The following hypotheses were generated based on findings in the literature on care giver's burden, as well as on findings on the stress-buffering role of social support. The hypotheses will be divided under the following headings: burden in relation to patient's characteristics, burden in relation to the care giver's characteristics, burden in relation to site, and burden in relation to social support.

Burden in relation to patient's characteristics

Hypothesis 1. There will be a significant relationship between objective burden experienced by the care giver of the mentally ill patient and the severity of patient's behavioral disturbance.

Hypothesis 2. The longer the duration of the patient's behavioral disturbance, the higher will be the level of objective burden experienced by the care giver.

Hypothesis 3. Care giver's subjective burden will be significantly correlated with the severity of the patient's behavioral disturbance.

Hypothesis 4. The longer the duration of the patient's behavioral disturbance, the higher will be the care giver's subjective burden.

Hypothesis 5. The change in patient's level of social role functioning will be significantly correlated with the extent of care giver's objective burden.

Hypothesis 6. The change in patient's level of social role functioning will be significantly correlated with the level of care giver's subjective burden.

Hypothesis 7. There will be a significant relationship between patient's demographic characteristics and the care giver's objective burden.

Hypothesis 8. There will be a significant relationship between patient's demographic characteristics and the care giver's subjective burden.

Burden in relation to care giver's characteristics

Hypothesis 9. Objective burden experienced by the care giver will be significantly related to his/her demographic characteristics.

Hypothesis 10. Subjective burden experienced by the care giver will be significantly related to his/her demographic characteristics.

Burden in relation to site

Hypothesis 11. There will be a significant difference between the amount of objective burden experienced by care givers of the in-patients and of those visited in the community.

Hypothesis 12. There will be a significant difference between care givers of the in-patients and of those visited in the community in the amount of reported subjective burden.

Burden in relation to social support

Hypothesis 13. Frequency of social contact made by the care giver with members of his/her social network will influence the amount of objective burden experienced.

Hypothesis 14. Frequency of social contact of the care giver with members of his/her social network will be significantly correlated with the level of subjective burden experienced.

Hypothesis 15. The amount of tangible assistance received by the care giver will be significantly correlated with objective burden.

Hypothesis 16. The amount of tangible assistance received by the care giver will be significantly correlated with the reported subjective burden.

Hypothesis 17. Care giver's satisfaction with the help received will be significantly correlated with the extent of objective burden.

Hypothesis 18. Care giver's satisfaction with the help received will be significantly correlated with the extent of subjective burden.

CHAPTER III

METHODS

Subjects

The convenience sample was drawn from the population of primary care givers/significant others of Bahraini mentally ill adults. Twenty three primary care givers were interviewed by the researcher. Ten of the subjects were recruited from the population of care-givers whose patients were living in the community, and were receiving the services of the psychiatric hospital's community department. The remaining 13 subjects were care givers of Bahraini patients who had recently been admitted to 4 acute inpatient units in the psychiatric hospital. The criteria for patients' selection included nationality, age and diagnosis. Patients whose care givers were selected for the study had to be of Bahraini nationality, aged between 20 to 59 years, and diagnosed according to ICD-9 of any category of mental illness excluding mental retardation, drug or alcohol addiction and Alzheimer's disease. The number of previous admissions to the psychiatric hospital was not a condition for selection.

For both community and inpatient groups, the next of kin was selected as the care giver and informant if he/she

was the spouse or the parent. Next of kin, other than spouses, were chosen as primary care givers/informants on the basis of relationship to patient, living in the same household, amount of daily contact, and type of activity performed by the care-giver for the patient including care of the patient during illness. Siblings or other relatives were selected as substitutes to the above if they met the criteria for selection.

In two inpatient cases when the spouses were not available for interview, a parent and an aunt were selected as informants/care givers based on relationship to the patient, frequency and amount of daily contact, and care during illness. At times when more than one relative was present during the interview, the informant data were collected and recorded on only one of the them who happened to meet most of the criteria. This happened on 6 occasions.

Male care givers constituted 39% (n=9) of the study sample and females 61% (n=14). The community sub-sample consisted of 90% females (n=9), while this figure was 51% (n=7) for the inpatient sub-sample. Ages of subjects ranged from 18 to 70 years ($\bar{M}$ =40.32, $\underline{SD}$ = 12.72). Of the total sample of informants/care-givers, spouses constituted 44% (n=10), mothers 26% (n=6), siblings 17% (n=4), while children and other relatives constituted 13% (n=3) of the total sample. Eighty seven percent (n=20) of the care-givers/informants were living at the same household as the

patients. All of the care givers in the community sub-sample were living at the same household as the patient. Of the total sample, one of the care givers was a student, while 52% (n=12) were homemakers. In the community sub-sample, homemakers constituted 80% (n=8) of the total. Thirty five percent of the informants were illiterate, 22% received primary education (grade school), and nearly 38% finished their intermediate or high school education.

The patients (N=23) whose care givers were the subjects of this study consisted of 35% males (n=8), and 65% females (n=15). Female patients made up 60% (n=6) of the community group while 69% (n=9) of the inpatient group were females. The patients' ages ranged from 24 to 59 years ($\bar{M}$ = 36, SD =10.58). Married patients constituted 61% (n=14) of the total population while 22% (n=5) were single and 17% (n=4) were divorced and widowed. Thirty nine percent of the patients (n=9) were illiterate, 17% (n=4) finished primary school, and a similar number finished intermediate school and high school. Only 8.7% (n=2) had college education. The patients' diagnoses consisted of 57% (n=13) schizophrenic disorders, 26% (n=6) depressive disorders, 8.7% (n=2) other diagnoses and a similar percentage as undiagnosed conditions. Patients diagnosed as having schizophrenic disorders constituted 80% (n=8) of the community group while the inpatient group consisted of 38% (n=5) of patients with this diagnosis. Major depressive

disorders constituted 20% (n=2) of the community group and 30% (n=4) of the inpatient group. The duration of illness or onset of trouble as reported by the family care giver ranged from less than one month to 15 years for the entire sample. The patients and their care-givers' places of residence were distributed proportionally across all areas of Bahrain.

Instrument

The instrument used in this study was based on the Social and Behavioral Assessment Schedule (SBAS) designed by Platt, Weyman, Hirsch and Hewett (1980). The SBAS has been specifically designed to evaluate the behavior and social performance of psychiatric patients; and to assess the impact of treatment regimes on the patient and his/her significant others 'subjective and objective burden' (Platt et al, 1980). The authors explain that while the schedule was designed to assess the burden of acute psychiatric illness, it can also be adapted to assess the impact of physical illness and chronic conditions generally. All the sections of the schedule, except for section 5, cover the past month. The schedule consists of 239 items administered in a standardized semi-structured format by a trained interviewer and takes 45 to 75 minutes to complete. The author recommends that the informant be a closely involved relative or a friend on whom the patient decides. The criteria for choosing the appropriate informant, however,

consist of face to face contact, living in the same household and a hierarchy of relatives. Although spouses and parents are usually chosen as informants, the authors recommend that the SBAS can be administered even if patient and informant do not live in the same household, provided there exists a close relationship and regular contact.

The structure of the original SBAS

The schedule consists of six sections with sections 2, 3, and 4 forming the central core of the schedule, and each dealing with a different aspect of the patient's situation (Platt et al, 1980). The remaining subsidiary sections (1, 5, and 6) provide contextual and background information on the patient and informant. The authors also explain that all sections and sub-sections of the schedule can be used independently of each other or omitted as necessary.

Psychometric properties of the SBAS include high inter-rater reliability. Inter rater reliability was established by four raters on SBAS interviews on the objective and distress sub-scales of the three major sections on behavior, social performance, and adverse effects 'burden' (Weisman et al, 1981; Platt et al, 1980). Agreement between pairs of raters for total score of the six sections ranged from .92 to .99 for Inter Class Coefficient Correlation (I.C.C), and .87 to .98 for Kendal's W coefficient. In addition, item analysis show that 89% of the behavior scale items, 85% of the objective burden items and 75% of the subjective burden

items achieved a value of > 0.80 on weighted kappa analysis.

The validity of the SBAS has also been demonstrated. Gibbons and associates (cf. Platt, 1985, p392) report significant correlations between informant scores on the General Health Questionnaire and total distress score on the SBAS. The same authors also report significant correlations between objective burden and both disturbed behavior and limited social performance of patient (Platt et al, 1980; Weissman et al, 1981; Platt, 1985). In addition, some studies demonstrated the sensitivity of the SBAS burden scales to changes in the patient's behavior (Platt, 1985). The principal author reported that the schedule was translated to German and Spanish among other languages and that these versions were reported to have had achieved a satisfactory degree of reliability and validity (S. Platt, Personal communication, March 21, 1990).

The modification of the SBAS

The semi-structured interview schedule designed for this study was based on the SBAS. The schedule was first written in English. It was then translated by the investigator to Arabic in order to facilitate its use with Arabic speaking subjects. The Arabic version was then checked by two persons for technical and grammatical relevancy and accuracy, and corrections were made as necessary. Three sections of the schedule were back-translated to English. Sections 1,3, and 5 were selected

randomly and re-translated to English by three persons who had no previous access to the original version. The back-translated version exactly matched the original in its contextual meaning except that some English terms such as distressed, and annoyed were translated to disturbed, and angry respectively. Resignation was also translated as 'becoming used to it'. Initially, the schedule was pilot tested on 3 care givers who were accompanying their mentally ill relatives to the psychiatric hospital outpatient department. This resulted in a slight modification of the schedule by deleting several items in section 6 as they were shown to be less relevant.

The modified schedule is composed of 180 items designed to assess the nature and degree of burden experienced by the patient's care-giver in relation to patient's variables such as demographic characteristics, duration of illness, severity of behavioral disturbance (psychiatric symptoms) and change in level of social role performance, as well as the care-giver's characteristics which include gender, age, level of education, and knowledge about the patient's illness. In addition, it also looked at the informant/care-giver extent of contact and help received from his/ her informal and formal support system. The schedule consists of 6 sections which cover the past month.

Sections 1 and 2 of the modified schedule pertains to demographic information about the patient, the informant,

composition of the household, patient history and frequency of contact between patient and informant. In addition, the two sections included items relating to the presence of physical illness, disability or handicap in the patient, patient's pre-morbid characteristic, care giver's knowledge of illness and his/her perception of the causes, other ill members in the family requiring care, and history of mental illness in the family.

Section 3 assesses the patient's social role functioning, or change in performance in certain key areas of his/her social roles. Social role functioning is operationally defined as the patient's performance of certain tasks which pertains to his/her social roles as a parent, spouse, or significant other. Therefore the change in social role performance is the degree or level of patient's functioning or performance in these roles compared to his/her best performance before the illness or the recent trouble. Six areas are assessed with a total of 11 items: two items on domestic role performance (household tasks, and household management); 3 items on parental role performance (child care, interest in child, child discipline); one item each on spare time activities and social life; two items on informant-patient relationship (everyday conversation, support, affection and friendliness); and one item each on work/study role performance, and participation in decision making. Each of the 11 items is rated on a scale of 0= same

performance, to 3= no longer performs this task. Patients who have no children or are single score 9 (non-applicable) on the parental role performance. The mean score of these ratings provides the change in social performance score. Each of the items are also rated on a 5 point duration scale, from 0= less than a week, to 5= deficit of role performance has always been present. The mean score of these ratings provide the duration of change in social role performance score.

Section 4 of the schedule measures the patient's behavioral disturbance. Information is gathered about 21 behaviors (correlates of psychiatric symptoms) which include misery, withdrawal, slowness, forgetfulness, underactivity, overdependence, indecisiveness, worrying, fearfulness, obsession, irritability, rudeness, violence, parasuicide, offensive behavior, self neglect, complaints about body aches and pains, and odd behavior. Each of the 21 behaviors is rated on a 3 point severity scale ranging from 0= non or very little, to 2= severe. The sum of these ratings provides the behavioral disturbance severity score. The same 21 items are then each rated on a duration scale of 1= behavior evident for less than a week, to 5= behavior has always been present. The mean score of these ratings provides the behavioral disturbance duration score. The informant's distress in relation to these behaviors is measured by one item of rating scale with 4 points ranging

from 0 to 8, with 0= none, 1= moderate, 2= severe, and 8= resignation. In addition, an open question was included here on the perception of the care giver as to the most agonizing aspect of caring for his/her mentally ill relative.

Section 5 of the schedule is an objective measure of the adverse effects, 'burden', of the patient's illness on the care-giver and others inside and outside the household. The schedule consists of 10 items pertaining to 9 areas which included the care-giver's physical health, his/her emotional health, social life, leisure time, disposable income, work/study performance, time off work/study, disruption of his/her life, effects on household relationships and effects on others outside the household. The items were similar to those of the SBAS except for the deletion of items relating to effects on the children. Three rating scales were used to measure each item. The first of these rating scales is the objective scale which measures the presence of or extent of the care-giver's burden. The anchors are defined specifically for each item, on a 3 point scale ranging from 0 to 2, with 0= little or none, 1= moderate and 2= severe. The sum of the ratings provides the objective burden score. The second rating scale pertains to the duration of burden experienced by the care-giver, and consists of 5 points ranging from 1= less than a week to 5= always. The mean score of these ratings provides the duration of objective burden. The 3rd rating

scale is the subjective burden scale which measures the extent of distress reported by the care-giver in relation to the particular burden present. The scale consists of 4 points from 0 to 8 with 0= none, 1= mild to moderate, 2= severe, and 8= resignation. Resignation scores were calculated separately from other scores of subjective burden. Resignation was scored when the care-giver expressed no distress despite the presence of the problem and reported that he/she has got used to it. The average score of the other ratings on the scale provides the subjective burden score.

The last section, 6, relates to the social support system available for or utilized by the care giver. It consists of 8 items, of which three items (relatives, friends/neighbors, and social services) are similar to the items of the SBAS. In addition to the items given in the SBAS, this section included items relating to the formal and informal social agencies with which the patient and his/her care-giver may come into contact in the Bahraini culture. These included the community psychiatric nurse, native healers such as Mulla (religious, spiritual healer); herbalist; fortune teller which in some cases may also prescribe herbal or remedial potions; and zar performer (Exorcist of demons/ spirits). Each item in this section has four rating scales. The first rating scale measured the frequency of contact the care-giver had during the past

month with each of the social sources mentioned. The rating scale consists of 5 points ranging from 0 to 4, with 0= no contact, 1= at least once, 2= once a week, 3= less than 3 contacts/week, and 4= daily. The sum of these ratings provides the frequency of social contact score. The second rating scale assessed the relatedness of those contacts to the patient. It is a nominal scale with 0= no, and 1= yes. The sum of these ratings provide the extent of relatedness of social contact to the patient. The third rating scale assessed extent of help received by the care-giver from each of these resources in the form of tangible assistance, goods or services. The scale consists of 3 points ranging from 0 to 2 and defined as follows: 0= no help, 1= some practical help, and 2= took over one or more responsibilities. The mean score of these ratings provides the perceived amount of tangible assistance received. The third scale measures the care-giver's perception of relief in relation to the help received. It consists of 3 points ranging from 0 to 2 and defined as follows: 0= no relief, 1= some relief, and 2= considerable relief; could not cope otherwise. The mean score of the ratings provides the extent of care giver's perception of relief as a result of the help received.

One open question is also added to this section which assessed the care-giver's perception of the kind of assistance needed most in caring for the patient in the community.

Setting and procedure

The study proposal was forwarded to the Human Subject Committee in the University of Wisconsin hospital, whose approval was obtained prior to conducting the study in the Government Psychiatric hospital in Bahrain. Permission for conducting the study in the Psychiatric hospital was sought and secured from the medical chief of staff in the Ministry of health, the chairman of the Psychiatric hospital and the senior nursing officer. The nursing staff in 2 female and 2 male acute admission units as well as those in the psychiatric community department were notified about the study by the senior nursing officer.

The investigator then sent memoranda to these units explaining the nature of the study, the criteria for patient selection and the procedure for recruitment of family care giver subjects. Recruitment forms, laying out the guidelines for choosing the appropriate primary care giver/informant, were also sent. The staff were asked to inform patients' next of kin about the study at the time of the patients' admission to the hospital, to identify an appropriate care giver, to obtain his/her initial consent for the interview and to inform the researcher as soon as possible. The researcher then either contacted the care giver by phone or met with him/her during the hospital visiting hours and arranged for an in-person interview. In some cases, however, the staff failed to inform the

researcher on the first day of admission. This resulted in the interviews being conducted from the 2nd to the 5th day of admission. In addition, care givers of 4 eligible inpatients (f=3, m=1) who met the criteria for selection were not included in the sample due to the following reasons: failure of the staff to inform the investigator at an early time, refusal of the care giver to be interviewed, difficulty in tracing a significant other, and inconvenience due to long travelling distance.

For the community group, the subjects were selected on a day to day basis from the daily log of visits scheduled for that particular day by the community nurses. The two available community psychiatric nursing teams who alternatively worked in the morning and the afternoon shifts helped in recruiting the subjects. The researcher accompanied one of the teams either in the morning or in the afternoon shift and selected the first patient on the visiting list of that shift who met the criteria for selection. In addition, the criteria of having a significant other living with the patient in the same house, caring for him/her, or in frequent contact with him/her were also included as a condition for selection. The community nurse made the initial contact with the patient and his/her significant other who is selected as a care-giver/informant by the same criteria used for the inpatient population. She then introduced the researcher and secured

an initial consent for the interview. In-person interviews were conducted with the care-giver at his/her home at the same time of introduction without the presence of the patient or the community nurse.

Prior to each interview, the purpose and nature of the study were explained to each care giver and an oral assent was obtained. Confidentiality was assured and the care giver was informed of his/her right to refuse an interview or to stop at any point if she/he wished. A copy of the consent form was given to each care-giver as pertinent, but some of the illiterate subjects did not see it necessary. On average, each interview lasted approximately 50 minutes. The patients' diagnoses were obtained from the nursing staff following permission of the psychiatrist and the senior nursing officer. The data collection procedure lasted from July 1st to August 1st 1989.

CHAPTER IV

RESULTS

Descriptive statistics and inferential statistics were used in data analysis. Descriptive statistics are presented here for most of the variables studied so as to provide a clear picture about the characteristic of the subjects studied as well as the care giving situation. Chi-square, analysis of variance (ANOVA), and Pearson Product moment Correlation Coefficient, were used to test the hypotheses at two-tailed significance. Some of the categories of demographic variables were collapsed into fewer categories in order to provide sufficient numbers for further analysis. Data obtained from the open questions are not analyzed in this report. Descriptive data of all the variables will be presented first followed by findings related to the research hypotheses.

Characteristics of the Patients

The illness' characteristics

The patients who had been ill from one week to less than 3 months constituted 17% (n=4) of the total and they were all in the inpatient group. Nearly 73% (n=17) of the patients had been ill for more than 2 years. Those who had been ill for more than 10 years constituted 39% (n=9) of the

total patients. About half of the patients (52%) were reported to have had a relapse or their condition necessitated an admission within a one year period at the time of the interview. The number of admissions to the psychiatric hospital ranged from 1 to 15 ($\bar{M}$ = 4.7, $\underline{SD}$ = 3.6) with nearly 48% of the patients (n=11) having been admitted 5 or more times. However, the troubled behavior of 87% of the patients were described by their care giver as not persistent. Only 39% (n=9) of the care givers perceived that their patients' condition was severe while the same percentage reported that it was not severe. Seventy eight percent of the patients (n=18) were reported to be taking prescribed psychotropic medication at the time of the interview.

The scores on the behavioral disturbance severity scale ranged from 1 to 25 ($\bar{M}$ = 11.61, $\underline{SD}$ = 6.32). 'Complaints about body aches and pains' by patients was the most frequently reported behavior. It was reported by 82% (n=19) of the care givers. This was followed by 'worry' (62%); 'irritability', 'underactivity', and 'forgetfulness' (57%); 'misery' and 'odd ideas' (52%); and 'withdrawal', 'slowness', 'overdependence', and 'self neglect' (48%). 'Parasuicide' and 'offensive behavior' were the least reported behaviors. The patients' behavioral disturbance reported by the care givers varied in duration from 3 months to have 'always' been present. The majority of the

disturbances were reported to have existed for more than one year. However, behaviors such as 'irritability' and 'misery' were largely reported to have been present from one week to less than 3 months.

Social role functioning

Of the total patients, 43% (n=10) were reported to have been employed in the past, and only 13% (n=3) were currently employed. The last time of employment for those who were no longer working ranged from 3 years to 22 years. Therefore, thirteen percent (n=3) were reported to contribute financially to the household at the time of the interview.

The scores on the change in patients' social role performance rating scale ranged from 0 to 3 with a mean of 1.21 (SD= .79). The most frequently reported changes in social roles were in the areas of work/and or study, offering support to informant, and spare time activities. Sixty one percent of the patients (n=14) were reported in each of those categories. This was followed by changes in household tasks (57%), interaction with the informant (52%), and being affectionate and friendly to informant (49%). The least amounts of change were reported to have occurred in the area of household management and sharing in decision-making.

The duration of changes in social role performance ranged from less than a week to more than one year, with 65% being of more than one year in duration. Some changes were

reported to have taken place from three months to less than a year, but very few were described to have been present 'always'.

There was a positive relationship between the amount of change in role performance and the duration of this change, $r = .44$, $P < .05$, and a positive relationship between the amount of change in roles performance and the degree of behavioral disturbance, $r = .66$, $P < .001$. No relationship was found between the degree of behavioral disturbance and the duration of change in social role performance.

As regards to the relationship between these aspects and the patients' demographic characteristics, few significant relationships were found. There were some differences in level of disturbance and social functioning in relation to patient's gender, education, and marital status (see Tables 5, 6 & 7). Male patients in this sample were found to be associated with longer duration of change in social role performance ($M = 4.12$, $SD = .44$) than did the female patients ($M = 2.80$, $SD = 1.66$), $F(1,21) = 4.82$, $P < .05$. Another significant difference was found in the area of duration of disturbance. The non-married group had these behaviors for a longer duration ($M = 3.85$, $SD = .42$) than did the married group ($M = 3.18$, $SD = .82$) $F(1,21) = 5.09$, $P < .05$. As regards to education, those of higher education had more admission ($M = 7.83$, $SD = 3.76$) than did the illiterate group

($\bar{M}$ = 4.55, $\underline{SD}$ = 2.50) or those of lower education ($\bar{M}$ = 2.50, $\underline{SD}$ = 3.07), $F(2,20) = 5.23$, $\underline{P} = <.01$.

Analysis of variance showed some differences between the in-patients and those from the community in the aspects of level of disturbance and change in social role performance (see Table 8). The behavioral disturbance of the community patients was of longer duration ($\bar{M}$ = 3.97, $\underline{SD}$ = 1.33) than the inpatient group ($\bar{M}$ = 3.04, $\underline{SD}$ = .76), $F(1,21) = 20.36$, $\underline{P} < .001$. The other significant difference was found in the area of social role performance, where the community patients were reported to have more changes in social role performance ($\bar{M}$ = 1.41, $\underline{SD}$ = .87) than did the inpatients ($\bar{M}$ = .78, $\underline{SD}$ = .57) $F(1,21) = 4.37$, $\underline{P} < .05$.

Care givers' characteristics

Sixty percent of the community subsample were illiterate compared to 15% of the inpatient subsample. Those who had high school or higher education comprised 38% of the inpatient group and 10% of the community group. However, when it came to knowledge of patient's diagnosis or names of medications, the majority of care givers lacked knowledge in this respect. Almost none of the care givers knew the names of the medication taken by the patient, but they could describe them, eg., "he takes a large white pill three times a day" etc. This may be due to the fact that the drugs names were written in English on the container. Twenty six percent of the care givers ($n=6$) knew the

diagnoses of their patients, while the rest referred to the illness as 'nerves', even though 65% of care givers (n=15) reported a previous history of mental illness in the family.

Eighty seven percent (n=20) of the informants were living in the same household as the patients. Ninety percent of the community subsample (n=9) reported that they have face-to-face contact with the patient almost all day long. Majority of the care givers of the inpatient subsample (77%), however, reported a daily face-to-face contact with the patient, while 15% (n=2) reported lesser frequency of contact. Those who reported higher frequency of contact were female home-makers, while the majority of those reporting lesser frequency were employed male care givers. In addition, a significant number of those caring for non-married patients (78%) reported an all-day contact in comparison to 21% of those caring for married patients, χ^2 (df,2)= 11.74, $P < .01$. The duration of care reported by care givers ranged from three months to nearly 23 years. Twenty two percent of care givers (n=5) reported caring for another ill family member besides the patient.

Relationship between care givers' characteristics and patients' characteristics

The analysis of variance indicated differences in the mean scores in various areas of the patient's illness characteristics in relation to the care giver's demographic characteristics (see Tables 9, 10 & 11). The female care

givers reported a higher degree of change in patients' role performance ($\underline{M}$ = 1.32, $\underline{SD}$ = .79) compared to the male care givers ($\underline{M}$ = .65, $\underline{SD}$ = .56) $F(1,21)= 4.88$, $\underline{P} < .05$. There was also a significant difference in the reported duration of the change between the male care givers and the female care givers. The females reported longer duration of changes ($\underline{M}$ = 3.73, $\underline{SD}$ = 1.12) than did the males ($\underline{M}$ = 2.52, $\underline{SD}$ = 1.75) $F(1,21)= 4.14$, $\underline{P} < .05$.

There were also differences in mean scores of the patient's characteristics in relation to care giver's education. Illiterate subjects' reported significantly longer durations of both behavioral disturbances and the changes in social role performance. The mean scores for the duration of behavioral disturbance was 3.79 ($\underline{SD}$ = .52) for the illiterate subjects compared to 2.74 for the more educated ($\underline{SD}$ = .62) $F(2,20)= 4.84$, $\underline{P} < .01$. Non significant differences were found in the type of relationship of care giver to the patient.

Care Giving Burden

Objective burden and its duration

Objective burden scores ranged from 0 to 9 ($\underline{M}$ = 3.83, $\underline{SD}$ = 2.64). Sixty two percent of the care givers ($n= 14$) reported physical ill health. In second place, emotional ill health, curtailment of leisure time activities, and financial difficulties were reported by 52% ($n=12$) by the

care givers. Care givers who reported physical ill health reported it in the severe burden category, while majority of other problems were reported to be moderate (see Table 12).

The mean scores for the duration of the various objective burdens ranged from nil to 'always', with the majority (57%) being in the category of more than 'one year' duration. Seventy seven percent (n=10) of care givers who reported physical ill health and 91% of those with emotional ill health reported them to be present from 3 months to more than a year. However, 50% of those reporting curtailment of leisure time activities and 75% of those with financial difficulties reported that these have always been present (see Table 13). The extent of objective burden was positively and significantly correlated with the duration of burden, $r = .56$, $P < .01$.

Subjective Burden and resignation

The subjective burden mean scores ranged from 0 to 2, ($M = .67$, $SD = .58$), with 35% (n=8) of the care givers having a mean score of 0, and 26% (n=6) having a mean score of 1. The mean scores for resignation ranged from 0 to 4 ($M = .48$, $SD = 1.08$), with 78% (n=18) of the subjects scoring a zero. Of those who reported physical ill health, 57% reported moderate to severe distress, while 77% of those with emotional ill health, and 91% of those with financial burden reported a moderate to severe distress (see Table 14). The subjective burdened correlated positively and significantly

with objective burden and its duration. Resignation is also positively and significantly correlated with objective burden, $r = .54$, $P < .01$, but non-significantly with the duration of burden.

Social Support Measures

The frequency of social contact total scores ranged from 2 to 12 ($M = 6.0$, $SD = 2.54$). The most social contact reported was with family and relatives. The contact frequency ranged from once a month to daily, with the majority of care givers reporting at least three times a week or more contacts. Some (26%) reported daily contact with family members and relatives. Contacts with neighbors and friends was also highly reported with only 9% ($n=2$) reporting no contact in the last month. Almost all of the care givers (96%) had no contact with any social worker during the past month. Forty eight percent of the care givers ($n=11$) reported being visited by the community psychiatric nurse, with the majority reporting once-a-month visits. The traditional healers who were contacted most by the care givers were the Mulla (26%), followed by the herbalist (22%). The other two, the fortune teller and the zar performer, were contacted little or not at all (see Table 15).

On whether this contact was pertaining to the patient, the scores ranged from 0 to 4 ($M = 1.95$, $SD = .88$). Seventy eight percent of family and relative contacts were found to

be pertaining to the patient, while only 4% (n=1) of the contacts with neighbors were found to be as such. All of the community psychiatric nurses' visits, as well as majority of contacts made with the Mulla (83%) and the herbalist (71%) were made in relation to the patient (see Table 16).

The mean scores of tangible assistance received by the care givers ranged from 0 to 1.75 ($\bar{M}$ = .81, $\bar{SD}$ = .44). Seventy eight percent (n=18) of care givers reported receiving practical assistance from family and relatives (This took the form of help with domestic chores, taking the patient to medical appointment, and financial and material assistance). Only 8.7% (n=2), however, reported receiving tangible assistance from friends and neighbors (see Table 17). All those who were visited by the community nurse or those who contacted native healers reported a moderate amount of assistance (This took the form of goods and services, and in a few cases material assistance).

The mean scores of the perceived relief as a result of assistance received by the care givers ranged from 0 to 2 ($\bar{M}$ = 1.06, $\bar{SD}$ = .52). Nearly 100% (n=18) of care givers receiving assistance from family and relatives perceived it to be helpful with 44% (n=8) reporting that they could not manage without it. Also 75% of those receiving financial assistance from social services (N=3) stated that they could not manage otherwise. Majority of those visited by the

community nurse and those contacting a herbalist reported some degree of relief as a result of the help received (see Table 18).

Testing of the Research Hypotheses

Burden in relation to patient's characteristics

Findings indicate no significant relationship between objective burden and the severity of the patient's behavioral disturbance (see Tables 26). This leads to rejection of hypothesis 1.

On the other hand, both objective burden and duration of burden were correlated positively with the duration of the disturbance, $r = .58$, $P < .01$, for objective burden and $r = .52$, $P < .01$, for the duration of the burden. Therefore, there is evidence to support hypotheses 2 which states that there will be a significant relationship between care giver's objective burden and the duration of patient's behavioral disturbance.

There was a trend for subjective burden to be correlated with the duration of the disturbance $r = .36$, $P < .10$, but not significantly correlated with the severity of the disturbance. Therefore, the results do not support hypotheses 3 and 4 which predict that the care giver's subjective burden will be significantly correlated with the severity and duration of patient's behavioral disturbance. Similarly, there was a trend for resignation to be

correlated with the duration of the disturbance, $r = .37$, $P < .10$.

In contrast, the care giver's distress and resignation due to the patient's behavioral disturbance showed an increase in relation to the severity of this disturbance. The findings also indicated that a longer duration of behavioral disturbance was associated with resignation while shorter duration of disturbance was associated with severe distress.

Care giver's distress due to the patient's disturbed behavior also showed an increase in relation to the recency of the trouble. Patients with an illness of less than 5 years caused more distress in their care givers than those who had the illness or the onset of trouble for more than 5 years. In addition, 61.5 % of the inpatient group reported severe distress due to patient's behavior compared to 30% of the community group. Furthermore, severe distress was reported by more male care givers than female care givers.

Analysis also showed that objective burden and its duration were not significantly correlated with the extent of change in social role performance, nor with the duration of this change. Therefore hypothesis 5 is not supported.

On the other hand, care giver's subjective burden is significantly correlated with the extent of change in patient's social role performance, $r = .44$, $P < .05$, and the duration of this change, $r = .51$, $P < .01$. Therefore, there

is evidence to support hypothesis 6 which predicts that the care giver's subjective burden will be significantly correlated with the change in patient's social role performance. No significant relationship was found, however, between resignation and change in social role performance nor with the duration of this change.

As regards to the Patient's demographic characteristics, no significant relationships were found between objective burden and patient's age, gender, marital status or education (see Tables 19, 20 & 21). The duration of burden was also not found to be related to any of those demographic characteristics. Therefore, hypothesis 7 which predicts that the patient's demographic characteristics will be significantly correlated with the care giver's objective burden is rejected.

In contrast, there were some significant relationships in the area of subjective burden; patient's age was found to be significantly related to subjective burden ($r = .50$, $p < .05$) and so was patient's gender. Care givers of male patients scored higher on subjective burden ($M = 1.07$, $SD = .46$) than those caring for female patients ($M = .46$, $SD = .53$) $F(1,21) = 7.47$, $p < .01$.

The mean scores for measures of subjective burden showed some differences between care givers of married patients and those of non-married patients. Care givers of the non-married patients showed a trend toward scoring

higher than those caring for married patients (see Table 20). However, subjective burden was not found to be related to the patient's educational level. Therefore, the results only partially support hypothesis 8.

On the other hand, no significant relationship was found between resignation and any of the patient's demographic characteristics.

Burden in relation to care giver's characteristics

No significant relationships were found between any of the care giver's demographic characteristics and the measures of objective burden, even though females, mothers and the illiterate subjects scored generally higher on objective burden than did others. Therefore, hypothesis 9 which predicts that objective burden experienced by the care giver will be significantly related to his/her demographic characteristics is rejected.

There were some differences in the mean scores of subjective burden measures in relation to care giver's demographic characteristics. The female care givers scored significantly higher on measure of subjective burden. The subjective burden mean score for females was .91 ($SD = .53$) compared to the males' score of .31 ($SD = .46$) $F(1, 21) = 7.70$, $p < .01$. On the other hand, care giver's age was not found to be significantly correlated with subjective burden. Although the scores showed some differences in relation to care giver's relationship to the patient, his/her marital

status and his/her educational level, none of these differences was significant (see Tables 22, 23 & 24). Therefore, hypothesis 10 is only partially supported.

Resignation mean scores were also found to be different for subjects of various levels of education, with those of moderate level of education scoring higher. However, none of the differences was significant.

Relationship between measures of burden and site

There were significant differences in measures of burden in relation to site (see Table 25). Mean scores of objective burden were higher for care givers in the community group ($\bar{M}$ = 6.10, SD = 1.66) compared to the care givers of the inpatients group ($\bar{M}$ = 2.07, SD = 1.75), $F(1, 21) = 31.07$, $P < .0001$. In addition, the community group reported longer duration of burden ($\bar{M}$ = 4.20, SD = .43) compared to the inpatient group ($\bar{M}$ = 2.81, SD = 1.77) $F(1, 21) = 4.37$, $P < .05$. Therefore, there is evidence to support hypothesis 11.

Community subjects also scored higher on subjective burden ($\bar{M}$ = 1.15, SD = .36) compared to the inpatient group ($\bar{M}$ = .30, SD = .41) $F(1, 21) = 26.22$, $P < .0001$. The results, therefore, support hypothesis 12. The resignation mean score was also higher for the community subjects but it was not significant.

Social Support in relation to Care giver's Burden

In the area of frequency of social contact, correlation coefficient indicate no significant relationships between the amount of care giver's social contacts and measures of objective and subjective burden (see Table 26). Frequency of social contact was not significantly correlated with care giver's objective burden, nor with the duration of this burden. This leads to rejection of hypothesis 13.

On the other hand, there is a trend for the frequency of social contact to be correlated with the amount of care givers' subjective burden, $r = .38$, $P < .10$. However, failure of the results to reach a level of significance leads to the rejection of hypothesis 14.

Relatedness of this contact to the patient was not significantly correlated with any of the measures of objective and subjective burden. The perceived amount of tangible assistance reported by the care giver also showed the same above pattern. This leads to rejection of hypotheses 15 and 16.

The care givers' perception of the helpfulness of the tangible assistance received yielded some significant relationships. The extent of relief reported was significantly correlated with objective burden, $r = .60$, $P < .01$. The findings, therefore, support hypothesis 17. In addition, the extent of relief as a result of tangible

assistance received was also correlated positively with the duration of burden, $r = .44$, $p < .05$.

No significant relationship was found between the extent of relief as a result of the assistance received and the care givers subjective burden. Therefore, hypothesis 18 is rejected.

In summary, measures of objective burden were found to be significantly higher in the care givers of the community group compared to the inpatient group. Objective burden was also found to be significantly related to the patient's duration of behavioral disturbance and to the care giver's perception of the helpfulness of the tangible assistance received, but not to any of the patient's or care giver's demographic characteristics.

Care giver's subjective burden was also found to be significantly higher in the community group. In addition, it was found to be significantly higher in care givers of males, of older, low functioning and non-married patients. Subjective burden was also found to be significantly higher in female care givers. On the other hand, care giver's distress due to the patient's behavioral disturbance was found to be significantly higher in care givers of the inpatient group, who also happen to score low on objective and subjective burden. As regards to social support measures, there was only a trend for subjective burden to be inversely correlated with the frequency of social support.

CHAPTER IV

DISCUSSION

The current study has aided in identifying relevant issues and main concerns of the particular group of care givers studied, i.e., the local care givers of the mentally ill patients in Bahrain, and therefore some of the findings may be specific to this culture. This study does not represent an effort to distinguish between two types of treatment programs per se, rather it serves to highlight the factors which interact to create burden on the care giver, and which are inherent in the characteristics of patients, their care givers and the care giving situation. In other words, the study findings have helped in identifying the highly at-risk groups of care givers who are greatly affected by the patients' illness regardless of the treatment setting.

The small sample size and the characteristics of the patients and their care givers limit one from making sweeping generalizations based on the findings of this study. Nonetheless, the study has replicated many of the findings in the previous literature, whether in relation to the patients' characteristics, informants/care givers' characteristic, burden, social support or the relationship between these variables. In the following paragraphs,

discussion will be made of the main findings of the study. This includes the descriptive data for each of the variables studied, as well as the relationship between those variables.

Patients' characteristics

In addition to the sample size limitation, the male patients were under represented in the overall sample in general and in the inpatient sub-sample in particular. Except for the gender factor, other patient's demographic characteristics seem to be well represented in the overall sample, with married patients being over represented in the inpatient group, while widowed, divorced and singled being clustered in the community group. This may be a factor in producing somewhat skewed results as regards to the sharp differences between the community and the inpatient groups. Furthermore, patients in the community subsample have been receiving the services of the community nurse because they are needy and disadvantaged, and the majority are of low socio-economic status. The care givers of these patients usually have difficulty in getting access to the outpatient clinic due to such reasons as non-affordable transport, living in remote towns and villages or lack of a resource person to accompany the patient to the outpatient clinic. This implies that the community sub-sample is a select group.

Findings also indicated differences between the community and the inpatient groups in terms of the extent of the behavioral disturbances reported and the duration of these disturbances. Illness duration varied in both groups, with the newly diagnosed and those in-episode being in the in-patient group. The community patients' mean scores were higher in this respect compared to the in-patient group as manifested by the duration of the behavioral disturbance and the duration of the change in social role performance. In comparison to the patients of the community subsample, the majority of the inpatients were married females, who were highly functional before the episode, and who were reported to have a greater degree of behavioral disturbance, accompanied by an acute change in social role performance.

Findings on the patients' illness characteristics, particularly those related to the patients' disturbed behaviors and the social role dysfunctions have replicated previous findings which assessed these areas. The most frequently reported disturbance was complaints of body aches and pains by the patient, which is indicative of either the nature of their illness, side effects of psychotropic medications, or their preoccupation with bodily symptoms due to their confinement to the house and their lack of social involvement. Other behavioral disturbances such as irritability, and misery were also mentioned by Platt and his associates to had been reported frequently by the care

givers in their study (Platt et al. 1981). However, unlike Platt's findings, parasuicide and offensive behavior were the least or not at all reported by the care givers in this study. A possible explanation for this is the prevalent religious beliefs and attitudes as well as the socio-cultural norms which prohibits such conduct. Social desirability may have also affected the care giver's responses in this aspect. That is, the care givers were reticent to report such behaviors to the interviewer.

Although the majority of the sample was females (60%), it is still surprising that only 13% of the total sample, who happen to be males, are employed. The reason for unemployment among men was deterioration in condition following the illness, while for females, the explanations for not working included lack of skills, inability to find a job, lack of opportunity, marriage, or that work is not seen as necessary. Yet, none of the care givers seemed to be disappointed at the female being unemployed. Care givers of male patients, however, seemed to be resigned blaming the patient's inability to work on the illness. This raises the speculation that patient's gender may be a factor affecting care giver's expectations of various roles played by the patient. In the area of changes in social role performance, most of the changes reported by care givers were in the areas of work/ study performance, spare time activities, offering support to the informant and household tasks.

Responses indicated that not many changes occurred in the areas of household management and sharing in decision making. This is because the patients were not doing these tasks even when they were well. It seems that the patient's marital status and his/her level of functioning affect whether or not the patient would be involved in decision making.

Relationship between the patient's characteristics and the care giver's characteristics

Similarly, the care givers in the community and the inpatient subsamples were also different in terms of demographic characteristics. The community care givers were generally older, predominantly females home-makers and largely illiterate, while relatively young, educated male spouses were more represented in the inpatient group. Hence, the finding concerning more objective and subjective burden in the community group in comparison to the inpatient group. A plausible explanation for this discrepancy, is that in a traditional society such as Bahrain, the next of kin, who usually happens to be a male, is the one who acts as spokesman for the family as it interfaces or interacts with other social systems. Therefore a male relative may be responsible as a next of kin to deal with the health care system on behalf of the patient, even though the patient may be cared for at home by a female relative. This female relative is usually a

mother, a sister, or a member of the in-laws in an extended family. In a nuclear type family, where the male spouse is usually holding an outside employment and is out part of the time, the responsibility for care falls on an older daughter or a sister. This factor in many cases creates an interference with these care givers' needs and interests. For not only their social life, physical and emotional health suffer, but also their schooling and academic achievement if they are still attending school.

Although not frequently reported, violent behavior whenever present was usually associated with high levels of distress in the care giver. Care givers of violent patients expressed their distress and embarrassment at having to resort to the help of neighbors to control the patient or to summon the help of police whenever the patient becomes violent and difficult to manage or when he/she needs to be committed to the hospital. This type of behavior was mostly reported in younger patients especially males. A middle aged mother spoke of her distress whenever her son becomes disturbed and dangerously threatens a family member. She also spoke of the frustration in negotiating the mental health system when such a crisis occurs and her difficulty in getting help in time.

In addition, other care givers of violent patients, especially those who were single or lived in the parent's household, spoke of the disruption this caused other members

of the family who feel neglected, because the patient's needs were treated as a priority by the parents. This factor was reported to cause friction between family members due to disagreement over the patient's management. The persistently low functioning and highly disruptive patients were reported by care givers to cause strain on household relationships, curtail the care givers' social life and leisure activities, cut them off friends and place financial burden on them due to them seeking treatment alternatives in the hope for a miracle improvement in the patient's condition. Parents, especially mothers, were more concerned in this regard as they worry about what will happen to the patient or who is going to care for him/her when they are gone.

The findings in this respect lend support to previous studies on care givers of the mentally ill in western cultures (Lefely, 1987a, Hatfield, 1979). Mothers in this case usually feel responsible and bear the blame for the patient's behavior. A mother stated that she feels torn between attending to the patient's needs and fulfilling her responsibility toward other members of the family. This care giver of a young patient who was low functioning and manifested great degree of behavioral disturbance, spoke of the family's desperate need for respite care for the patient, or a program which helps to get the patient out of

the house for part of the day and engage him in some constructive activity.

The patient's behavior is more difficult to deal with when it is complicated by the presence of other disturbances such as self neglect and dependency. Dependency by the patient seems to be stressful to the care giver.

Confinement of the patient to the house all day seem to add to this distress. This is particularly true in the case of male patients, who cannot be accommodated in the routine of the care giver who is usually a female. This was reported to be even more complicated when the patient was demanding or had dirty personal habits. Females who were mostly homemakers reported that this adds to their daily chores and depletes their physical energy.

Measures of Burden

The findings of this study need to be viewed within the total context of other important factors involved, such as the patient's and care giver's demographic characteristics and the care giving situation. The main findings of this study indicate that objective and subjective burden are very significantly high in care givers of the community group in comparison to the inpatient group. Looking at the characteristics of both the patients and the care givers in each group, one can understand the reasons for these sharp differences.

Results have shown that the main burdens reported by the care givers are those relating to physical ill health, emotional ill health, curtailment of leisure activities and social life, and financial difficulties. These types of burdens were also associated with great extent of subjective burden as well as resignation in the care giver. In particular, the physical ill health, emotional ill health and financial burdens created severe distress in the care giver. The findings in this respect are a close replication of those reported in earlier studies by Grad & Sainsbury (1968), Platt & Hirsch (1981), and Lefley (1987b).

Relationship between patients' characteristics and measures of burden

The characteristics of the patients in the inpatient and the community subsamples help in establishing a basis for understanding the significant differences between the two settings in measures of burden. Moreover, these burdens increased with the duration of the patient's illness, the duration of change in social role performance and the duration of the behavioral disturbance, but not with the severity of this disturbance.

Two adverse effects which were reported by many previous studies, but were least reported by the care givers in this sample were the effects on the household, disruption of others' life and disruption of the informant's life.

As regards to disruption of the household relationships, this was only reported in cases when the patient was demanding, violent, or quarrelsome. Although no question tapped the effects of the patient on children, some wives expressed their concerns in this regard, especially during times of acute episodes. Few care givers reported manifestations of emotional disturbances in other family members as a result of the patient's behavior.

Most care givers also denied disruption to their life due to the patient's illness, which may have necessitated them leaving the house in the previous month. However, all female spouses reported a pattern of leaving their husbands' homes in the past, and going to stay at their parents' home especially at the early stages of the illness. They also reported that this pattern had stopped as the patient's illness approached chronicity and as they learned to tolerate the patient's behavior as part of his illness. Most of these wives also happen to be blood relatives of their spouses and saw that accepting the patient's behavior is important for keeping the family together for the children's sake.

As regards to the male care givers, they reported keeping a low profile. They also reported a pattern of leaving the house for a short period of time and having some 'time out' especially when the patient is in an argumentative or a quarrelsome mood. These male care givers

explained that this allows the atmosphere to cool down in the house, and prevents things from getting out of hand. This method of coping was not reported by the females, probably due to the difference in gender roles and social expectations.

Disruption of the life of others outside the household was minimal, since the patients are usually confined to the house as much as possible. Another interesting fact is that low functioning patients regardless of their gender but mostly females, are not permitted to go out of the house on their own, but only if accompanied by another responsible family member. In addition, the family assumes full responsibility for insuring the patient's whereabouts at all times.

Severity of the patient's behavioral disturbance was correlated neither with objective, nor with the subjective burden. Although unexpected, this has replicated findings by Platt and his associates (1981). They reported that care giver's distress due to the objective burden (subjective burden) was less responsive to changes in the patient's behavior or the causative situation, in contrast to the distress resulting from the behavioral disturbance. This is supported by the finding of this study, that is distress and resignation associated with the severity of the behavioral disturbance were higher in the inpatient group of care givers, who at the same time reported lower objective

and subjective burdens. Many care givers reported feeling panicky, worried, anxious or afraid that something is going terribly wrong with the patient, or that they are losing him/her. Lack of knowledge about the nature of the patient's illness, side effects of medication, and lack of coping skills to deal with a novel and unfamiliar situation may be some of the reasons for this reaction. On the other hand, some care giver's distress was reported to be due to the intolerable behavior of the patient especially when they are disruptive, aggressive, argumentative, quarrelsome, or demanding. Others reported simply feeling exhausted due to the demands placed on their time and energy by the patient's illness and the resulting disruption in their role function. Some of these care givers who happened to be male spouses reported having to take over some of the patient's household tasks in addition to carrying on with their normal every day routine. This has implications for health providers who deal with these care givers and their mentally ill relatives on a day to day basis. Not only the needs of patients should be considered, but also the needs of their relatives as well. It is essential that the needs of care givers for information and reassurance about the patient's illness or the side effects of medication should be met by health professionals at all levels, and as much as humanly possible. These health providers should consider this as

their priority and should not see it as a wasted effort, even if the care givers are illiterate.

Subjective burden was also found to be correlated with the amount of change in patient's social role functioning and the duration of this change. The changes reported were mainly in the areas of household tasks, interaction with the informant, lack of leisure activity and work performance, which in a way reflect the gap created by the absence or lack of community support programs for these patients and their relatives. Programs such as vocational, rehabilitative, recreational and social skills training, would not only benefit the patients and improve their functioning but could also decrease the care givers' burden and distress resulting from having long contact hours with the patient.

Burden measures in relation to the care giver's characteristics

Many of these burdens were found to be higher in the community subsample who were mainly females, relatively older, and have longer contact hours with the patients. These care givers were caring for patients who were mostly single, widowed, or divorced, low in social functioning, and had been ill for longer duration. The burden reported may also be interactive, in that physical ill health and emotional ill health may also be due to additive factors besides the effects of the patient's illness, such as care

givers' age, their financial status and their social isolation. The care givers in this case are of low socioeconomic status, and themselves are dependent financially on other family members. Therefore, catering for the patient's needs adds more to their financial burden, and that is why they regard financial assistance to be a priority. Since medical treatment is provided freely in Bahrain, the financial burden is not related to the costs of patient's treatment unless the family decides to treat the patient abroad. A few of these families reported receiving a social welfare allowance only if the family bread winner was disabled. In some cases, male patients who happened to be employed in the past were receiving a monthly allowance.

Again, the subjective burden was higher in the females specifically in the community subsample. Resignation in the care giver was more related to objective burden as well as the duration of this burden as is expected and was found in previous studies.

Findings indicate that the needs of care givers and their mentally ill relatives are not static or identical but individually vary according to the patient's circumstances, and those of his or her care giver and the care giving situation. This is an important issue to consider if treatment programs are to be more effective.

Social Support measures

The data suggest that family members in this culture are the major providers of support whether in terms of social contact, or tangible help. Contact with immediate family members was also a source of emotional support to many of the care givers. The role of the significant other here consisted of providing the care giver with advice, encouragement, counseling and reassurance. However, when it comes to self disclosing information about the patient's behavior or problems to other relatives or friends, most of the care givers denied doing that as they didn't wish their private life secrets to be known to others outside of the house.

Other social networks varied in the type of social support provided for or sought by the care giver. The main social support function served by neighbors and friends was that of social contact but very little in regard to tangible assistance. This should not lead us to underestimate the role played by these networks in socialization, provision of frame of reference, emotional support and advice to the care giver. Only a small percentage of the care givers reported lack of contact with their neighbors. Severity of the patient's behavioral disturbance is usually a factor in preventing these carers from exchanging visits with their neighbors or friends.

Most of the contacts made with traditional healers were made in relation to the patient. They were mostly made by the care givers of the newly admitted patients prior to bringing the patient into hospital. This indicates that these informal agencies continue to be the primary sources of contact in the help seeking process by some people especially in regards to mental or emotional disturbances. Regarding the perception of helpfulness of the assistance received, most care givers reported little or no satisfaction with this assistance. Some care givers continued seeking traditional treatment for the patient in addition to modern treatment, especially the spiritual type. Some families, however, reported seeking the help of these healers periodically. Such factors as loss of faith in the value of medical treatment, continued deterioration and lack of improvement of the patient usually motivate them to seek other alternatives to medical treatment.

The main functions served by the formal support systems, in this case the social services and the community psychiatric nurse, were mainly those of providing tangible assistance to the patients and their care givers in the form of administering treatment and financial or material aid. Low frequency of contact with these agencies indicate that other functions of support were minimal or non existing. Although majority of those visited by the community nurse expressed some satisfaction with the help received, a number

of them expected more from the community visits besides administering medications to the patient. Some, however, were not satisfied with other forms of support offered especially in relation to communication and advice.

The social contact and tangible assistance received may be seasonal and varies in type and amount according to other external factors. The time when this study was carried out, was a time of two festive occasions when social contact and tangible assistance were usually more intensive. This implies that social support should best be assessed on a long term basis by the use of a longitudinal design.

Social support and burden

The study has replicated some of the earlier findings on social support and care giver's burden. Analysis showed a strong trend for an inverse relationship between the frequency of social contact and care giver's subjective burden. This lends support to findings by Fiore and colleagues (1986) as well as Baillie and her colleagues (1988). Baillie and colleagues reported that perceived satisfaction with social support in the care givers of Alzheimer's patients was negatively correlated with the perceived stress. As regards to the interactive effects of social support, the sample size was limiting in terms of running more elaborate analysis. Therefore, there is not sufficient evidence to support or reject the role of the stress buffering role of social support.

The lack of relationship between the frequency of social contact and its relatedness to the patient indicates that other purposes were served by these contacts for the care giver. This was also true in relation to the tangible assistance reported by the care giver. Neither the relatedness of assistance to the patient, nor the amount of tangible assistance received by the care giver had any relationship to objective and subjective burden. This may be explained as either due to the tool used being non-specific in its assessment of the actual tangible assistance received, or that the help received by the care giver does not match his/her actual needs, implying that many of the problems responsible for creating objective and subjective burden for these care givers remain unresolved. Parallel to this is the explanation that while factors of objective burden are somehow chronic or of longer lasting nature, the help received may only be periodical or temporary. This needs to be investigated further by longitudinal design studies. There is also a need for alternative specific measures with highly established reliability and validity, which accurately assess psychological distress, and the actual amount and frequency of tangible assistance received.

The perception of the helpfulness of the assistance received was also positively correlated with the objective burden. Thus, lending support to findings reported by Scott and her associates (1988) who also found that care givers

who reported higher levels of burden, also reported receiving more than enough tangible assistance. Therefore, this cast a doubt on the suitability of the stress-buffering hypothesis in studying this type of social concept and outcome studied. Again, the question arises whether social desirability has affected the responses of care givers' in this sample. Despite the full explanation given in the beginning of the interview, some respondents, especially the illiterate, could have assumed that the researcher was a social worker or a hospital staff, as they are not fully familiar with the concept of research other than the public census. Another explanation may also be tied up to the one presented earlier, that is, the mismatch between the amount and type of tangible assistance given in relation to the nature of the burden experienced by the care giver.

Conclusion

Despite the limitations of the sample size, the study has identified many important factors in the patient's characteristics, in the care giver's characteristics, and in the care giving situation which influence the degree of burden and distress experienced by care givers in the culture of Bahrain. Some of the findings were specific to this culture, while others have replicated findings in previous literature on care giving burden. However, this fact does not cancel out the need for individualized interventions for the patients and their relatives.

Results indicated that care giver's objective burden was related to patient's duration of disturbed behavior. On the other hand, care giver's subjective burden was found to be significantly related to other patient characteristics such as age, gender, marital status and level of functioning. It is fair to conclude, therefore, that lack of availability of rehabilitative, vocational and support programs in the community to meet the special needs of such patients and their care givers, not only hastens patients' deterioration, but also adds to the difficulties of their care givers, resulting in ill effects such as physical ill health, emotional ill health, financial burden, social isolation and distress to the care giver. The care givers dissatisfaction with the treatment limitation to mere medication, reinforces the widely held professional opinion that medication should not be regarded as a panacea when it comes to treating the mentally ill patients in the community.

Although objective and subjective burden were not related to all of the care giver's demographic characteristics, there is a strong evidence that female care givers of all ages experience higher levels of distress and resignation as a result of continuous contact with and caring for low functioning patients. In particular, subjects in the community group reported highly significant levels of objective and subjective burden. Again, this may

be due to factors inherent in the characteristics of the care givers or the care giving situation, such as lack of personal and social resources. Moreover, these care givers seem to have to put up with the patient's behavior for longer durations due to the inconvenience of getting the patient to hospital in time as well as total dependence on the community nurse's visits.

In general, the Bahraini care givers seem to be fully committed to caring for the ill family member, and none of them expressed a need for separation from the patient. Nevertheless, some care givers expressed the need for respite care, especially when the care giver is middle aged or an elderly and the patient's illness is complicated by such disabling behaviors as dependency, violence, self neglect or dirty habits. In this case some expressed the need for respite care or that the hospital should share the responsibility for caring for the patient.

In addition, the study has also identified the various factors related to the patients' illness which influence the responses and needs of their care givers in various stages of the patient's illness; in particular, the care givers of the inpatients, where patients were mostly going through a current episode, or had the illness recently. These care givers expressed greater degree of anxiety, worry and psychological distress due to lack of knowledge about the patient's illness, and his/her strange behavior or how to

manage in this new situation. A need exists in this case for sympathetic reassurance, explanation about the nature of the patient's illness, involvement of the family members in the care decisions and counseling for relatives whose coping is threatened by the impact of the patient's illness.

The importance of counseling is underscored here, especially that many care givers in both groups manifested the need for an objective, empathetic and understanding listener. The findings on social support measures and their relationship to objective and subjective burden lend support to the argument advanced earlier. Informal support networks are the major providers of emotional and instrumental support, complemented by the formal networks whose support was mainly instrumental. Yet deficits are evident judging by the findings. A deficit was detected in the aspect of self disclosure especially in relation to the problems of patients management and its effects on the household. The formal agencies have a role to play here especially that confidentiality is an issue for care givers who feel reluctant to disclose these difficulties to people in their social circle.

Recommendations

Based on findings of this study as well as previous literature, many implications have emerged for research and practice in this area of health care. Implications and recommendations for research will be discussed here first,

followed by recommendations which are specific to the practice in Bahrain.

Research

In order to clarify inconsistencies, future studies addressing care givers of the mentally ill should aim toward systematic exploration of various aspects of social support in relation to coping and burden. This may be in the form of group intervention or by assessing naturally occurring social networks. In addition, the concepts of social support, coping and burden should be investigated using longitudinal designs and larger samples.

More specifically to Bahrain, this study should be replicated using a longitudinal design, and with a larger sample, randomly selected from the population of Bahraini care givers.

Practice

The study findings have many implications for mental health and psychiatric nursing practice in Bahrain. Firstly, the findings on objective and subjective burden in relation to the patient's characteristics, spelled out very clearly the need for re-orientation of the treatment approaches used with this population. Community programs should be established to meet the rehabilitative, vocational, and support needs of these patients. The psychiatric department should initiate and coordinate such programs in joint collaboration with other ministries such

as housing, transportation, labor and social affairs, youth and sport council as well as other voluntary organizations.

Secondly, the significantly high levels of burden experienced by care givers in the community group, especially female home-makers, imply that suitable intervention programs should be established; programs tailored to meet the specific needs of this highly at risk population. Self help groups are highly commended, and proved to be effective in western cultures. In Bahrain, where families and relatives are the major sources of support, this may or may not be applicable. At any rate, psychiatric nurses and psychiatric social workers have a great role to play in providing information, education about the illness, side effects of medications, patients management, and stress management, and counseling.

Thirdly, community programs aimed at providing services for these patients and their care givers should be subjected to frequent evaluations and monitoring. Not only cost effectiveness should be a criteria for evaluating such programs, but also quality assurance.

Finally, since the health services in the country are adapting primary health care approach, it is inherent in this approach that the clients, i.e., individuals, families, and local communities should be actively involved in their own health care. This needs to be considered in planning future programs for these patients and their relatives.

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APPENDICES

Appendix A
Tables

Table 1

Percentages of patients (N=23) in relation to type and degree of behavior disturbances

Behavior	Degree of behavioral disturbance		
	0	1	2
1. Misery	48	30	22
2. Withdrawal	52	30	17
3. Slowness	52	39	9
4. Forgetfulness	44	56	-
5. Underactivity	44	30	26
6. Overdependence	52	17	30
7. Indecisiveness	56	35	9
8. Worry	39	39	22
9. Fear	61	13	26
10. Obsession	78	9	13
11. Odd ideas	48	44	9
12. Overactivity	91	4	4
13. unpredictability	57	30	13
14. Irritability	44	22	35
15. Rudeness	74	13	13

Table 1 cont.

Behavior	Degree of behavior disturbance		
	0	1	2
16. Violence	61	30	9
17. Parasuicide	87	13	-
18. Offensive behavior	96	4	-
19. Self neglect	52	30	17
20. Complaints about body aches & pains	17	74	9
21. Odd behavior	74	22	4

Note. The anchor points are indicative of the degree of the disturbance as follows: 0= none or mild, 1= moderate, 2= severe.

Table 2

Percentages of patients (N=23) in relation to the duration of behavioral disturbances

Behavior	Duration					
	1	2	3	4	5	9
1. Misery	-	26	9	17	-	48
2. Withdrawal	-	13	9	26	-	52
3. Slowness	-	9	4	35	-	52
4. Forgetfulness	-	13	9	30	4	44
5. Underactivity	-	9	9	39	-	44
6. Overdependence	-	4	4	30	9	52
7. Indecisiveness	-	-	9	26	9	57
8. Worry	-	-	4	48	9	39
9. Fear	-	9	4	26	-	61
10. Obsession	-	9	-	9	4	78
11. Odd ideas	-	17	9	30	-	44
12. Overactivity	-	-	-	9	-	91
13. Unpredictability	-	4	4	35	-	57
14. Irritability	-	30	4	13	4	48

Table 2 cont.

Behavior	Duration					
	1	2	3	4	5	9
15. Rudeness	-	9	-	17	4	70
16. Violence	-	13	-	22	-	65
17. Parasuicide	-	9	-	4	-	87
18. Offensive behavior	-	-	-	4	-	96
19. Self neglect	-	13	9	22	4	52
20. Complaint of body aches & pains-	-	13	13	57	-	17
21. Odd behavior	-	9	17	13	-	74

Note. The anchor points indicate the duration of the behavior as follows: 1= <1 week, 2= >1 week to <3 months, 3= >3 months to < 1 year, 4= >1 year, 5= always, 9= non-applicable.

Table 3

Percentages of patients (N=23) in relation to changes in social role performance compared to prior levels

Social Role	Level of performance				
	0	1	2	3	9
1. Household Tasks	17	17	22	17	26
2. Household management	13	9	9	9	61
3. Participation in child care	26	13	13	13	35
4. Interest in child	44	4	13	9	30
5. Disciplining child	35	17	13	4	30
6. Spare time activity	39	22	35	4	0
7. Interaction with informant	44	22	22	9	4
8. Offering support to informant	35	17	30	13	4
9. Affection/ friendliness	52	26	13	9	0
10. Work/study performance	35	13	22	26	4
11. Sharing in decision making	57	13	13	4	13

Note. The anchor points are as follows: 0= same or more, 1= less, 2= a lot less, 3= no longer doing this task, 9= non-applicable/ didn't do this task even when well.

Table 4

Percentage of patients (N=23) in relation to duration of change in social role performance

Social role	Duration					
	1	2	3	4	5	9
1. Household tasks	-	13	4	35	4	44
2. Household management	-	4	-	13	9	74
3. Child care	-	4	-	30	4	61
4. Interest in child	-	4	-	17	4	74
5. Disciplining child	-	9	-	26	-	65
6. Spare time activities	-	13	4	39	4	39
7. Interaction with informant	-	17	4	26	4	48
8. Offering support to informant	-	13	4	39	4	39
9. Affectionate/friendly	-	13	4	26	4	52
10. Work/study performance	-	9	4	48	-	39
11. Sharing in decision-making	-	4	-	17	9	70

Note. The anchor points are indicative of the following:

1= <1 week, 2= >1 week <3 months, 3= >3 months <1 year, 4= >1 year, 5= always, 9= non-applicable.

Table 5

Mean scores of patient's behavioral disturbance and change in social role performance in relation to patient's gender

Pt's charact.	Patients' Gender			
	Male		Female	
	(n=8)		(n=15)	
	<u>M</u>	<u>SD</u>	<u>M</u>	<u>SD</u>
Degree of disturbance	12.12	7.70	11.33	5.72
Duration of disturbance	3.51	.73	3.41	.79
Number of admissions	5.62	4.44	4.20	3.12
Change in role perform.	1.21	.24	0.98	.98
Duration of change	4.12	.44	2.80	1.66

Table 6

Mean scores of behavioral disturbances and change in social role performance in relation patient's marital status

Pt's charact.	Marital status			
	Married		Sgl/Wd/Dv	
	<u>M</u>	<u>SD</u>	<u>M</u>	<u>SD</u>
Degree of disturbance	11.85	5.95	11.22	7.21
Duration of disturbance	3.18	.82	3.85*	.42
Number of admissions	3.92	4.05	5.88	2.52
change in role performance	0.93	.81	1.25	.69
Duration of change	3.12	1.52	3.46	1.51

Note. * $P < .05$.

Table 7

Mean scores of behavioral disturbances and change in social role performance in relation to Patients' education

Pt's charact.	Education level					
	IL		P/I		Sc/C	
	<u>M</u>	<u>SD</u>	<u>M</u>	<u>SD</u>	<u>M</u>	<u>SD</u>
Degree of disturbance	9.66	6.53	12.50	4.64	13.33	8.04
duration of disturbance	3.79	.66	3.26	.79	3.18	.80
Number of admissions	4.55	2.50	2.50	3.07	7.83*	3.76
Change in role perform.	.98	.97	1.02	.58	1.22	.74
Duration of change	3.02	1.84	2.75	1.48	4.01	.42

Note. * $P < .10$

The education level symbols are as follows: IL= Illiterate, P=primary, I= intermediate, Sc= secondary, C= college.

Table 8

Mean scores of the patient's behavioral disturbance and change in social role performance in relation to site

Pt's charact.	Site			
	Community		Inpatient	
	(n= 10)		(n=13)	
	<u>M</u>	<u>SD</u>	<u>M</u>	<u>SD</u>
Degree of disturbance	12.60	7.35	10.84	5.58
Duration of disturbance	3.79**	.31	3.04	.76
Number of admissions	4.90	2.85	4.53	4.20
Change in role perf.	1.41*	.87	.78	.57
Duration of change	3.72	1.33	2.90	1.56

Note. * $P < .05$, ** $P < .01$.

Table 9

Mean scores of patient's behavioral disturbance and change in social role performance in relation to care giver's gender

Pt's charact.	Care giver's gender			
	Female		Male	
	(n=14)		(n=9)	
	<u>M</u>	<u>SD</u>	<u>M</u>	<u>SD</u>
Degree of disturbance	12.42	6.70	10.33	5.80
Duration of disturbance	3.63	.56	3.15	.95
Number of admission	5.00	3.82	4.22	3.38
Change in role perform.	1.36*	.79	.65	.56
Duration of change	3.73*	1.12	2.52	1.75

Note. * $P < .05$.

Table 10

Mean scores of behavioral disturbance and social role performance
in relation to care giver's education

		Education level					
		I		P/I		S/C	
Pt's charact.		<u>M</u>	<u>SD</u>	<u>M</u>	<u>SD</u>	<u>M</u>	<u>SD</u>
Degree of disturbance		9.75	5.37	12.55	7.95	12.66	5.05
Duration of disturbance		3.79*	.52	3.60	.77	2.74	.62
Number of admission		4.00	2.27	4.22	3.07	6.33	5.50
Change in role perform.		1.09	.57	.86	.89	1.30	.85
Duration of change		3.60	1.48	2.94	1.81	3.26	1.05

Note. * $P < .05$.

The above points are indicative of the following:

I= illiterate, P/I= primary to intermediate level,

S/C= secondary to college.

Table 11

Mean scores of behavioral disturbance and change in role performance in relation to care giver's relationship to the patient

		Type of relationship					
		spouse		parent		other	
		(n=10)		(n=6)		(n=7)	
Pt's charact.	<u>M</u>	<u>SD</u>	<u>M</u>	<u>SD</u>	<u>M</u>	<u>SD</u>	
Degree of disturbance	12.30	5.83	12.50	8.20	9.85	6.40	
Duration of disturbance	3.40	.84	3.83	.59	3.17	.73	
Number of admissions	3.90	4.55	6.00	2.28	4.71	3.04	
Change in role perform.	.83	.64	1.25	.95	1.22	.80	
Duration of change	2.74	1.66	3.83	1.67	3.88	.89	

Table 12

Percentages of care givers (N=23) reporting objective burden

Variables	Degree of burden		
	0	1	2
1. Physical ill health	39	17	44
2. Emotional ill health	48	44	9
3. Social life	83	9	9
4. Leisure activity	48	39	13
5. Disposable income	48	39	13
6. Work/ study performance	74	26	-
7. Time off work/study	92	4	4
8. Disruption of inf. life	100	-	-
9. Household relationships	91	9	-
10. Disruption of others' life	87	13	-

Note. The above anchor points for objective burden scale refer to the following: 0= none or little, 1= moderate, 2= severe.

Table 13

Percentages of the care givers (N=23) in relation to duration of objective burden

Variables	Duration					
	1	2	3	4	5	9
1. Physical ill health	-	4	13	30	13	39
2. Emotional ill health	-	-	13	35	4	48
3. Social life	-	-	4	4	9	83
4. Leisure time	-	9	-	22	22	48
5. Disposable income	-	-	-	13	39	48
6. Work/study performance	-	4	4	18	-	74
7. Time off work/study	-	4	4	-	-	92
8. Disruption of inf. life	-	-	-	-	-	100
9. Household relationships	-	-	4	4	-	92
10. Disruption of others' life	-	4	-	9	-	87

Note. The above scale of duration of burden refer to the following: 1= < 1 week, 2= > 1 wk to < 3 months, 3= > 3 months to < 1 year, 4= > 1 year, 5= always, 9= N/A.

Table 14

Percentages of care givers (N=23) reporting subjective burden

Variables	Degree of subjective burden				
	0	1	2	8	9
1. Physical ill health	13	22	13	13	39
2. Emotional ill health	4	31	13	4	48
3. Social life	9	4	-	4	83
4. Leisure time	39	9	-	9	44
5. Disposable income	-	26	22	4	48
6. Work/ study performance	17	13	-	4	65
7. Time off work/study	4	4	-	-	92
8. Disruption of inf. life	-	-	-	-	100
9. Household relationship	-	4	9	-	87
10. Disruption of others' life	4	4	4	-	87

Note. The anchor points of the distress scale refer to the following: 0= none or mild, 1= moderate, 2= severe, 8= resignation, 9=N/A.

Table 15

Percentages of care givers (N=23) in relation to frequency of social contact made within the previous month

Social contact	Frequency of contact				
	0	1	2	3	4
1. Family/Relatives	-	35	22	17	26
2. Friends/ Neighbors	9	39	4	13	35
3. Social services	96	4	-	-	-
4. Community psych. nurse	52	39	9	-	-
5. Mulla	74	17	4	4	-
6. Herbalist	78	22	-	-	-
7. Fortune teller	87	9	4	-	-
8. Zar performer	100	-	-	-	-

Note. The above anchor points indicate the following:

0= no contact, 1= once a month contact, 3= twice a month contact, 4= more than 3 times a week contact.

Table 16

Percentages of care givers (N=23) reporting a contact relating to the patient

Social contact	Relatedness to patient		
	Yes	No	N/A
1. Family/Relatives	78	22	-
2. Friends/ Neighbors	4	78	17
3. Social services	13	4	83
4. Community psych. nurse	48	-	52
5. Mulla	22	4	74
6. Herbalist	22	8	70
7. Fortune teller	13	4	83
8. Zar performer	-	-	-

Table 17

Percentages of care givers (N=23) who reported receiving tangible assistance

Social contact	Degree of assistance			
	0	1	2	9
1. Family/Relatives	22	30	48	-
2. Friends/ Neighbors	74	4	4	17
3. Social services	9	13	4	74
4. Community psych. nurse	-	48	-	52
5. Mulla	4	22	-	74
6. Herbalist	-	17	-	83
7. Fortune teller	4	9	-	87
8. Zar performer	-	-	-	100

Note. The anchor points indicate the following:

0= none, 1= little, 2= moderate, 9=N/A.

Table 18

Percentage of the care givers (N=23) reporting relief as a result of assistance received

Social contact	Degree of perceived relief			
	0	1	2	9
1. Family/Relatives	-	43	35	22
2. Friends/ Neighbors	4	-	4	91
3. Social services	-	4	13	83
4. Community psych. nurse	-	39	9	52
5. Mulla	13	9	4	74
6. Herbalist	4	13	-	83
7. Fortune teller	9	4	-	87
8. Zar performer	-	-	-	100

Note. The anchor points are indicative of the following:

0= no relief, 1= little relief, 2= couldn't cope
otherwise, 9= N/A.

Table 19

Mean scores of measures of burden in relation to patient's gender

Burden measures	Pt's Gender			
	Female		Male	
	(n=15)		(n=8)	
	<u>M</u>	<u>SD</u>	<u>M</u>	<u>SD</u>
Objective burden	3.86	2.99	3.75	1.98
Duration of burden	3.07	1.74	4.06	.62
Subjective burden	.46	.53	1.07	.46
Resignation	.33	1.05	.75	1.16

Table 20

Mean scores of measures of burden in relation to the patient's marital status

Burden measures	Pt's marital status			
	Married		sgl/wd/dv	
	(n=14)		(n=9)	
	<u>M</u>	<u>SD</u>	<u>M</u>	<u>SD</u>
Objective burden	3.07	2.55	5.00	2.45
Duration of burden	3.28	1.16	3.63	1.40
Subjective burden	.90	.63	.52	.51
Resignation	.50	1.28	.44	.72

Table 21

Mean scores of measures of burden in relation to patient's level of education

Burden measures	Level of education					
	I		P/I		S/C	
	(n=9)		(n=8)		(n=6)	
	<u>M</u>	<u>SD</u>	<u>M</u>	<u>SD</u>	<u>M</u>	<u>SD</u>
Objective burden	4.66	2.34	3.12	2.53	3.50	3.27
Duration of burden	3.98	.43	2.97	2.10	3.16	1.60
Subjective burden	.97	.54	.36	.51	.65	.58
Resignation	.66	1.41	.37	1.06	.33	.52

Note. I= illeterate, P/I= Primary to intermediate, S/C= Secondary to college.

Table 22

Mean scores of measures of Burden in relation to care giver's gender

Burden measures	Care giver's gender			
	Female		Male	
	(n=14)		(n=9)	
	<u>M</u>	<u>SD</u>	<u>M</u>	<u>SD</u>
Objective burden	4.36	2.53	3.00	2.74
Duration of burden	3.56	1.56	3.20	1.48
Subjective burden	.91	.53	.31	.46
Resignation	.50	.94	.44	1.33

Table 23

Mean scores of measures of Burden in relation to care giver's educational level

Burden measures	Educational level					
	I		P/I		S/C	
	(n=8)		(n=9)		(n=6)	
	<u>M</u>	<u>SD</u>	<u>M</u>	<u>SD</u>	<u>M</u>	<u>SD</u>
Objective burden	4.12	2.23	4.33	3.24	2.66	2.16
Duration of burden	3.65	1.56	3.60	1.47	2.83	1.60
Subjective burden	.97	.55	.53	.55	.48	.60
Resignation	.25	.71	1.00	1.50	0.00	0.00

Note. The above categories are indicative of the following:

I= illiterate, P/I= primary to intermediate, S/C= secondary school to college.

Table 24

Mean scores of measures of burden in relation to care giver's relationship to the patient

Burden measures	Type of relationship					
	spouse		parent		other	
	(n=10)		(n=6)		(n=7)	
	<u>M</u>	<u>SD</u>	<u>M</u>	<u>SD</u>	<u>M</u>	<u>SD</u>
Objective burden	3.60	2.36	5.50	2.88	2.71	2.43
Duration of burden	3.89	.93	3.40	1.72	2.75	1.92
Subjective burden	.49	.45	.86	.48	.77	.79
Resignation	.70	1.49	.33	.55	.28	.75

Table 25

Mean scores of measures of Burden in relation to site

Burden measures	Site			
	Community		Inpatient	
	<u>M</u>	<u>SD</u>	<u>M</u>	<u>SD</u>
Objective burden	6.10***	1.66	2.07	1.75
Duration of burden	4.20*	.43	2.81	1.77
Subjective burden	1.15***	.37	.30	.42
Resignation	.80	1.32	.23	.83

Note. * $P < .05$, ** $P < .01$, *** $P < .001$.

Table 26

Variable Correlation Matrix

Variables											
Variables	1	2	3	4	5	6	7	8	9	10	11 12
1. BDN	1.00										
2. DBN	.56**	1.00									
3. SBN	.60**	.49**	1.00								
4. SRP	.33	.32	.44*	1.00							
5. DCG	.20	.12	.51**	.46*	1.00						
6. BHD	.21	.23	.14	.66**	.22	1.00					
7. DBD	.58**	.52**	.36+	-.02	-.16	.00	1.00				
8. SCT	-.26	.08	-.38+	-.25	.02	-.16	.05	1.00			
9. CPT	.19	.28	.10	.04	.00	.01	.21	.36+	1.00		
10. TA	.11	.24	-.04	.23	-.23	.17	.23	.11	.21	1.00	
11. REL	.60**	.43*	.33	.35+	.02	.36	.56**	.13	.22	.51	1.00
12. AGE	.05	.26	.50*	.05	.02	-.29	.03	.30	-.14	.37+	.24 1.00

Note. + $P < .10$, * $P < .05$, ** $P < .01$, *** $P < .001$.

The above variables are as follows: BDN= objective burden, DBN= duration of burden, SBN= subjective burden, SRP= change in social role performance, DCG= duration of change in social role performance, BHD= behavioral disturbance, DBD= duration of behavioral disturbance, SCT= frequency of social contact, CPT= contact related to the patient, TA= tangible assistance, REL= perceived relief, and AGE= patient's age.

Appendix C : Personal communication.

Mr. Stephen Platt.
Medical Research Council,
Unit for Epidemiological studies in Psychiatry,
University Dept. of Psychiatry,
Royal Edinburgh Hospital,
Morningside Park,
Edinburgh, EH10, 5HF
Scotland, U.K.

10th March 1990.

Dear Mr. Platt,

I am writing to you in regard to the Social and Behavioral Assessment Schedule (SBAS) , of which you are the principal author.

I am a graduate nursing student from Bahrain and currently in my second year of the graduate Psychiatric nursing program in the University of Wisconsin - Madison in the U.S.A. In partial fulfillment of the requirement for the master's program, I am doing a study on the burden experienced by the care givers of the Bahraini mentally ill adult patients. I am quite impressed with the SBAS as a reliable tool for assessing burden of significant others of this group of patients.

In reference to the articles written by you on validity and reliability of various measures of care giver's burden and those written by you and your colleagues about the SBAS in particular, I have decided that this tool would be most appropriate to use for the purpose of my study. Therefore, I have used the schedule as a basis for developing a format suitable for the Bahraini subjects of care givers. I have adapted sections 1,2,4, and 6 of the SBAS, omitting items related to the effects on children, sexual habits or heavy drinking in the patient, distress related to change in patient's social role performance and that related to the presence of behavioral disturbances. The items on social role performance, duration of change, duration of symptoms, objective burden, duration of objective burden, subjective burden, social contacts, relatedness to the patient, practical assistance received and the amount of relief reported were arranged into separate scales, but retaining the same anchor points and definitions. In addition to these items, the format developed consists of a number of open questions as well as certain items which are culturally relevant to Bahrain and pertinent to my research question.

Appendix B: Human Subjects Committee Approval

University of Wisconsin Madison

CENTER FOR HEALTH SCIENCES
Human Subjects Committee

H6/273
Clinical Science Center
600 Highland Avenue
Madison, WI 53792
(608) 263-2362

NOTICE OF APPROVAL

Meeting Date May 1 1989 Protocol Number 89-692-150

TO: Lulwa M. Mosalum
Graduate Student, School of Nursing
2302 University Avenue
Madison, WI

FROM: Jane C. Fitchen, *JCF*
IRB Administrator

RE: Protocol entitled, "The Burden of Caring for Community-Dwelling
Chronically Mentally Ill Adults in Bahrain"

The Human Subjects Committee has reviewed and approved the research protocol referenced above. Please note the following additional information and requirements:

INSTITUTIONAL ENDORSEMENT: If a granting agency requires notification of HSC approval, submit the name and address of an individual at the agency.

ADVERSE REACTIONS: If any serious, unexpected adverse reactions occur as a result of this study, you must notify the IRB Administrator immediately.

AMENDMENTS: If you wish to change any aspect of the study (such as design, procedures, consent forms, or subject population), please submit your requested changes, using a Change of Protocol form, to the administrator. The new procedure may not be initiated until HSC approval has been given.

RENEWAL: You are required to apply for renewal of approval every year for as long as the study is active. Contact the HSC office for renewal forms.

TERMINATION OF RESEARCH PROJECT: Please promptly notify the HSC of the termination of this project.

CONSENT FORMS: All subjects should be given a copy of the consent form(s).

The HSC suggests that you keep this memo with your copy of the approved protocol.

JCF/sjr

0656I

Initial Review - 5/31/89

XC: S. Ward

Bahrain is a small island in the Arabian Gulf. The official language used here is Arabic. Therefore, in order to facilitate the use of the tool with Bahraini subjects, I have translated it to Arabic. I would be grateful to get your opinion on this matter. I would also be interested to learn if the instrument or any modified version of it have been used in another culture and the degree of validity and reliability reported by those who used it.

I greatly appreciate your consideration and help in this matter and look forward to receiving your reply.

Yours sincerely,

Lulwa M. J. Mosalum

بسم الله الرحمن الرحيم

STATE OF BAHRAIN
MINISTRY OF HEALTH



الدكتور / محمد الحداد
رئيس مستشفى الطب النفسي
وزارة الصحة
ص. ب. ١٢٠
المنامة - البحرين

الى حضرة الفاضل الدكتور محمد الحداد المحترم

تحية طيبة وبعد

أكتب اليك هذه الرسالة راجيه منك التكرم بالسماح لي باجراء دراسة في مستشفى الطب النفسي .
كجزء من متطلبات درجة الماجستير في التمريض النفسي ، سوف أقوم باجراء دراسة عن طبيعة
المشاكل والصعوبات التي يواجهها أهالي المرضى النفسيين في المجتمع . وستكون عينة البحث
من أقارب المرضى البحرينيين الذين تتراوح أعمارهم من ٢٠ الى ٥٩ سنة والذين يتم إدخالهم
المستشفى للعلاج أو ممن يتربصون على العيادات الخارجية أو الذين تزورهم مرضاه المجتمع في
الفترة من يونيو الى أغسطس ١٩٨٩م حيث سأكون متواجده في البحرين .

سيتم الحصول على عينة البحث بمساعدة رؤساء ، رئيسات أجنحة الاستقبال في مستشفى الطب
النفسي . وستجمع المعلومات باجراء مقابلات شخصية مع أقارب المرضى القائمين على العناية بهم .
وسيتم ذلك في جو من السرية التامة ، وعند نشر النتائج سيراعى التحفظ على هوية المرضى
وأقاربهم وعدم نشر أية أسماء .

من الضروري أن أحصل منك على موافقة خطية وذلك لإبرازها للجنة مراقبة البحوث
Human Subjects Committee في مستشفى جامعة سكونسن والتي مهتمة بتقييم البحوث
المنجزة من حيث المحافظة على هوية الأشخاص المبحوثين .

لذلك سأكون شاكره لك اذا تكرمت بالتصريح لي كتابيا لاجراء هذه الدراسة في مستشفى الطب
النفسي .

هذا وتقبل مني جزيل الشكر والامتنان على تعاونك .

والسلام

approved

٢١٩/١/٨٩

Dr. Ahmed Abdulla Ahmed
CONSULTANT PSYCHIATRIST

Chief Medical Staff

التوقيع
لؤي محمد جاسم

Appendix D

Consent Letter

You are invited to participate in a study which I am undertaking for my masters degree in psychiatric nursing. The purpose of this study is to help us understand the types of problems that people face in caring for a mentally ill relative. If you choose to participate in this study , there will be no immediate personal or material rewards to you or to your mentally ill relative. But it is hoped that the results will help us know more about the difficulties which are faced by the mentally ill and their relatives in the community. Furthermore, these results may help us plan suitable programs for the mentally ill and their relatives.

There are no known risks associated with participating. The information will be collected with strict confidentiality, with no mention of any names. The results of this study will be published in a way that neither the participant nor their relatives can be identified.

If you participate in this study, you will be interviewed for one session lasting approximately one hour and 15 minutes. You do not have to answer questions if you do not want to. If you prefer not to participate, the care of your ill relative in the Psychiatric hospital will not be affected in any way.

If you have any questions, please feel free to ask. If you agree to participate but change your mind, you can stop at any time. If you think of any questions about the study at a later time, you may call me (Name and phone number was provided).

Appendix E: Instruction to nursing staff re- subjects' recruitment

To: Ward supervisors and nursing staff, Al Ghazali wards.
From: Lulwa Moh'd J. Mosalum, C.H.S.
Re: Collection of data for Master's Thesis.
Date: 6/ 25/ 89.

I like to inform you that I will be coming to your wards on a semi daily basis in order to interview the patients' relatives who will be the subjects of my study.

The recruitment of the subjects for this study will be done with your help. Therefore, your cooperation in this matter will be greatly appreciated.

The procedure for recruitment will be as follows:

I. Patients' selection:

1. Patients should be Bahraini.
2. The patients' ages should fall within the range of 20 to 59 years.
3. The patients' diagnosis include any mental illness except mental retardation, drug and alcohol dependence and senile or pre-senile dementia.
4. First admission or re-admissions.

II. On admission, please inform the next of kin of the following:

" A lecturer from the College of Health Sciences is doing a study on the problems faced by relatives who are caring for mentally ill patients. She would be interested to meet with you or any member of the family who takes care of the patient. If you agree, I will pass your name to her and she will contact you".

Please make sure that you give the message exactly as it is to all the potential subjects when admitting the patient.

If the next of kin is not a spouse or a parent, please use the enclosed recruitment form to find out the main carer of the patient and secure his/her willingness to be interviewed.

Once you get all of the above data, please supply me with the following: the name and phone number of the relative, as well as the patient's diagnosis.

I sincerely thank you all for your help and cooperation.

Recruitment Form

In case the next of kin is not the spouse, ask the following questions:

1. Relationship to the patient:
2. Do you live in the same household as the patient?
yes ----- no-----
3. How often do you see the patient?
 1. almost all day
 2. daily
 3. more than once a week
 4. once a week
 5. occasionally
4. Are you his/her only significant other?
yes----- no-----
5. Do you take responsibility for doing any of the following activities for the patient?
 1. taking care of hygiene, grooming.
 2. preparing food, washing and cleaning.
 3. supervision of medication.
 4. caring for him/her when very ill.

If answers no to questions 2, 4, and 5 then ask for name/s of person/s who care for the patient.

Appendix F

Section 1

I wonder if I could begin by asking you for a bit of background information about your relative to help me get a better overall picture of the situation.

PATIENT:

1. Gender: 1. Male 2. Female
2. Age in years: _____
3. Birth rank among sibling:
 1. oldest 2. middle 3. youngest
4. Marital status 1. Married 3. single
 2. Widowed 4. Separated or divorced
5. Relationship to informant:
 0. Spouse 3. Sibling 6. Other (specify)
 1. Parent 4. Other relative
 2. Child 5. Friend/neighbor(specify)
6. Living arrangement: 1) with informant 2) not with informant
7. Is patient's mother alive?
 - Yes----- (1)
 - No ----- (0)
8. Is patient's father alive?
 - yes _____ (1)
 - no _____ (0)
9. Level of education:
 1. Illiterate 4. High school
 2. primary 5. College
 3. Intermediate 6. University
10. How was the patient before the illness?
11. When did you first notice there was something wrong?
 - Rate onset of patient's trouble
 1. < 1 month 4. > 1 year < 2 years
 2. > 1 month < 3 months 5. > 2 years < 5 years
 3. > 3 months < 1 year 6. > 5 years < 10 yrs
 7. > 10 yrs

12. Since you first noticed that there was something wrong, has he/she been behaving strangely all the time?
Rate persistence of patient's trouble
0. Not persistent
1. Persistent
(if rating 0 ask question 13, if rating is 1 go straight to question 15)
13. When did the present trouble begin?
Rate onset of episode
0. < 1 week
1. > 1 week < 1 month
2. > 1 month < 3 months
3. > months < 1 year
4. > 1 year < 2 years
5. > 2 years
14. Since you first noticed that there was something wrong with the patient, has he/she got worse, stayed the same or got better.
Rate severity of patient's trouble
0. Less severe
1. The same
2. More severe
15. Could you tell me a bit more about what's been happening with the patient during the last 1 month?
16. Clinical diagnosis: _____
17. How many times the patient was admitted to the hospital before?
18. Can you remember when was the first time he was admitted?
19. Can you remember when was the last time he was admitted
20. Does the patient have physical illness?
Yes---- (1) No----- (0)
21. Does the patient have physical handicap?
Yes---- (1) No----- (0)
22. Does the patient have mental handicap?
Yes---- (1) No----- (0)
23. Is the patient on any medication
Yes----(1) No----- (0)
If no, go straight to question 22.

24. Can you tell me what medication he/ she is taking?
25. Has patient ever been employed?
Yes----- (1) No----- (0)
26. Is patient presently employed
Yes----- (1) No----- (0)
27. If no, when was the last time he/she was employed?
28. Occupation:
29. What are the reasons for unemployment?
30. Does patient contribute to household income?
Yes----- (1) No----- (0)

Section 2

Informant:

31. Gender : Male:----- (1) Female:----- (2)

32. Age in years-----

33. Marital status

- | | |
|------------|--------------------------|
| 1. married | 3. single |
| 2. widowed | 4. separated or divorced |

34. Level of education

- | | |
|-----------------|---------------------------|
| 1. illiterate | 4. high school(secondary) |
| 2. primary | 5. college |
| 3. intermediate | 6. university |

35. occupation

Describe household arrangement

36. Number of adults excluding informant and patient _____

37. Number of children _____

38. Responsibilities toward the patient
List tasks39. For how long have you been caring for the patient?
-----months

40. In the last month, how often did you see him/ her ?

- | | |
|-------------------|------------------------|
| 1. Almost all day | 4. once a week |
| 2. Daily | 5. At least once/month |
| 3. > twice a week | 6. only on admission |

41. In the last 3 months have you been caring for another family member? yes----- (1) no----- (0)

42. If yes, what condition that person is suffering? -----

43. Is there a known history of mental illness in the family?

yes----- (1) no----- (0)

44. Do you happen to know what condition your mentally ill relative suffers from?

45. What in your opinion has caused the patient's illness?

46. From where did you learn about the patient's illness?
- | | |
|----------------------------------|---------------|
| 1. health professionals(specify) | 4. A relative |
| 2. Neighbor/ friend | 5. Media |
| 3. past experience in the family | 6. Book |
| 7. other(specify) | |

Housing situation

Obtain the following information for both the patient and the informant:

47. Type of residence of patient
- | | |
|---|----------------------------|
| 0. whole house | 4. flat in high rise block |
| 1. self contained flat in fourth floor or above house | |
| 2. room(s) in house | 5. other (specify) |
| 3. flat in low rise block or in first 3 storey of high rise block | |
48. Type or residence of informant (if not living with the patient):
- | | |
|---|----------------------------|
| 0. whole house | 4. flat in high rise block |
| 1. self contained flat in fourth floor or above house | |
| 2. room(s) in house | 5. other (specify) |
| 3. flat in low rise block or in first 3 storey of high rise block | |
49. Type of ownership of patient's house
- | | |
|---------------------------------|----------------------------------|
| 0. owner occupied | 3. living with friends/relatives |
| 1. rented from private landlord | 4. hostel |
| 2. Government housing | 5. other (specify) |
50. Type of ownership of informant's house (if not living with the patient):
- | | |
|---------------------------------|----------------------------------|
| 0. owner occupied | 3. living with friends/relatives |
| 1. rented from private landlord | 4. hostel |
| 2. Government housing | 5. other (specify) |
51. How many rooms in the patient's house?
(rate density: number of persons divided by number of rooms, excluding kitchen, bathroom and lavatory).

Section 3

In the last month was the patient doing the same amount of the following activities as he/she did before his/her trouble began?

Rating: 0. same or more

1. somewhat less

2. much less

3. no longer doing this at all

9. not applicable (patient never did this activity even when was well).

activity

52. doing household tasks	0	1	2	3	9
53. managing the household	0	1	2	3	9
54. participating in child care	0	1	2	3	9
55. taking interest in children	0	1	2	3	9
56. disciplining children	0	1	2	3	9
57. spare time activities	0	1	2	3	9
58. daily interact with informant	0	1	2	3	9
59. offering support to informant	0	1	2	3	9
60. being affectionate/friendly	0	1	2	3	9
61. performance at work or study	0	1	2	3	9
62. sharing in decision making	0	1	2	3	9

How long is it since the patient's performance of the above activities changed?

Rating: 1. < 1 week

2. > 1 week < 3 months

3. > 3 months < 1 year

4. > 1 year

5. 'always'

9. not applicable

activity

63. doing household tasks	1	2	3	4	5	9
64. managing the household	1	2	3	4	5	9
65. participating in child care	1	2	3	4	5	9
66. take interest in child	1	2	3	4	5	9
67. disciplining children	1	2	3	4	5	9
68. spare time activity	1	2	3	4	5	9
69. interact with informant	1	2	3	4	5	9
70. offer support to inf.	1	2	3	4	5	9
71. affectionate/friendly	1	2	3	4	5	9
72. work/study performance	1	2	3	4	5	9
73. share in decision making	1	2	3	4	5	9

Section 4

I would like to ask you in more detail about how the patient was behaving the last month. I am going to run through a list of ways in which some people behave in these situations and may be you could tell me if your relative was like this.

74. In the last month was the patient miserable or in low spirits solemn or unsmiling? Did he/she cry, not respond to attempts to cheer him/her up or said life isn't worth living? was he/she miserable all the time?
0. no or little misery
 1. crying or obviously miserable for part of the time
 2. rarely cheerful; does not respond to attempts to cheer him/her up
75. Did your relative keep to him/herself to him/ herself? was he/she non-talkative or unsociable? did he/she reply when spoken to, or refused to meet people? was he/she like that all the time?
0. normally sociable
 1. socially withdrawn and solitary but will mix with others if encouraged to do so.
 2. never sociable even when encouraged to do so
76. Was the patient slow in his/her movement and activities? did he/she take a long time to get dressed, eat a meal, do the washing, etc.? Was he/she slow that he/she was dangerous.
0. none
 1. takes exceptionally long time to accomplish tasks.
 2. extreme slowness likely to cause danger to self or others.
77. Did your ill relative have difficulty in remembering everyday things or forget where he/she put things? did he/she forget he/she had done things that could cause damage, eg. while cooking? did he/she forget his/her way home?
0. none or infrequent
 1. definable lapses of memory
 2. so forgetful that cannot be trusted to do anything alone, eg. cooking, shopping, travelling.
78. Did your relative tend to do very little, sit for long periods of time, lie on his/her bed for long periods of time? did he/she spend most of his/her time doing nothing, or would he join some activity if you suggested it?
0. keep active most of the time without encouragement
 1. definable underactivity but responds to encouragement to do things

2. extreme underactivity, spends most of time doing nothing does not respond to encouragement.
79. Did the patient cling to you or follow around? was he/she unwilling to be left alone? did he/she refused to be left alone even for short periods of time?
0. normally independent
 1. follows others around for some of the time
 2. will not remain on own even for a few minutes
80. Did the patient find it difficult to make up his/her mind?
did he/she put off deciding about things, had difficulty deciding what to wear or whether to go out or stay at home? was he/she undecided that he/she didn't do things, eg. didn't go to work or school because he couldn't decide what to wear.
0. none
 1. some
 2. so indecisive and unable to make up his/her mind that other activities severely impaired.
81. Did your relative find every day events very worrying or anxiety provoking? eg. meeting friends, minor problems at work, or that something very terrible is going to happen?
did he/she worry about these difficulties all the time?
did he stop others doing things?
0. none
 1. some worries but not totally preoccupied by them
 2. extreme. Constantly concerned with worries or tries to change others' behavior because of worries.
82. Did your relative have any unusual fears, frightened of going out, of enclosed spaces, of animals or insects? was he/she so frightened that he/she avoided going out? avoided going in lifts etc.?
0. none or very little
 1. some unusual fears but no serious curtailment of activity
 2. fears so extreme that situation which provokes them is totally avoided
83. Was the patient fussy about doing things in a particular way? did he/she have a routine of doing things only in a certain way? did he/she kept checking on things or did things over and over again? did that affect his/her other activities, eg. going to work, school, etc.?
0. none
 1. some obsessional behavior but no serious curtailment of other activities

2. extreme obsessional behavior seriously curtailing other activities.
84. Did the patient express any strange or unusual ideas?
eg. saying that people are against him/her or wanted to harm him/her? was he/she jealous, said he/she was hearing voices, etc. Was the patient totally preoccupied with these ideas, was out of touch with reality?
0. none
 1. some odd/strange ideas, only minimal contact with reality
 2. extremely odd/strange ideas only minimal contact with reality
85. Was your relative unusually cheerful, excited or agitated?
- Was he/she noisy, restless, unable to sit through a meal?
- was she getting up at night doing day time activities?
- If you try to stop him/her from being active, would he/she respond to your efforts?
0. none
 1. behavior definably overactive but responds to efforts to control it.
 2. uncontrollable by others or controllable but overactive mostly at inconvenient time, eg. at night.
86. Did the patient say or do anything that was completely out of character? did he/she do or say something unexpected?
- did you never know what he/she was going to say or do next?
- did you think that he/she might suddenly do or say something which could have serious consequences?
0. none
 1. some unpredictability but not leading to doubts about fitness for responsibilities
 2. extreme unpredictability likely to have serious consequences for self or others

87. Was the patient irritable, snappy, quarrelsome, short tempered (with children). Was he/she like this all the time?
If you tried to change his/her mood, would he/she become less irritable?
0. none or very occasional
1. often irritable but responds to attempts by others to change his/her mood
2. always snappy and bad tempered with family (even if polite to outsiders)
88. Was the patient rude or inconsiderate to you or to friends or relatives? Was he/she bad mannered when people came to visit or when you went to see other people? would he/she apologize or try to be more polite?
0. none, very occasionally
1. some rude behavior, apologetic to people
2. always offends others with her/his rude behavior
89. Was the patient threatening or abusive towards you or anyone else? did he/she make verbal attacks on you or anyone else?
did he/she hit you or anybody else, broke furniture or damaged the house in a violent outburst?
0. none
1. threatening in manner and/or verbally abusive but did not strike anybody or cause damage to property.
2. hit person or destroyed property on at least one occasion.
90. Did the patient talk about taking his/her life? did he/she say deliberately harm him/herself, eg. by an overdose, slashing wrists, trying to gas him/herself?
0. none
1. threatened to deliberately harm self, but no attempt made
2. deliberately harmed self
91. Did your relative behave in a way that offended other people? eg. made sexual advances to friends or relatives, undress or exposed him/herself in public? Did this happen more than once?
0. none
1. offensive behavior on one occasion
2. offensive behavior on more than one occasion
92. Did the patient fail to look after him/herself? did he/she keep him/herself clean and tidy? was he/she eat properly. Did he/she take care of him/herself or eaten if somebody else suggested that?

- 0. none
 - 1. needs guidance and supervision to prevent self-neglect
 - 2. neglects self despite efforts of others
93. Did the patient look for sympathy about aches and pains?
or did he/she complain of tiredness or other body ills?
How often did he/she complain in this way?
- 0. none
 - 1. complained about bodily ills frequently but not every day
 - 2. complained about bodily ills on most days.
94. Did the patient do anything that was odd or unusual?
eg. muttering to him/herself in the street, dress in bizarre fashion, etc.? How often did he/she behave like this?
- 0. none
 - 1. some occasional odd behavior
 - 2. most of his/her behavior is idiosyncratic or bizarre.

Ask the following questions whenever a behavior is rated as present.

When did you first notice your relative behaving in this manner?

Rating: 1. < 1 week 4. > 1 year
 2. > 1 week < 3 months 5. 'always'
 3. > 3 months < 1 year 9. non applicable

	<u>Behavior</u>					
95. misery	1	2	3	4	5	9
96. withdrawal	1	2	3	4	5	9
97. slowness	1	2	3	4	5	9
98. forgetfulness	1	2	3	4	5	9
99. underactivity	1	2	3	4	5	9
100. overdependence	1	2	3	4	5	9
101. indecisiveness	1	2	3	4	5	9
102. worry	1	2	3	4	5	9
103. fear	1	2	3	4	5	9
104. obsession	1	2	3	4	5	9
105. odd ideas	1	2	3	4	5	9
106. overactivity	1	2	3	4	5	9
107. unpredictability	1	2	3	4	5	9

Section 5

I would now like to ask you a few questions about yourself and those in the household. I am interested to hear about any problems you've been having, and if you think they have been connected in any way with the patient's trouble. I would like to concentrate on what's been happening in the past 1 month.

118. In the last month have you suffered any illness or difficulty with your physical health?
0. no ill health
 1. some ill health but no treatment
 2. some ill health, treatment in progress
119. In the last month have you suffered any illness or problem with your emotional health?
0. no ill health
 1. some ill health but no treatment
 2. some ill health, treatment in progress
120. Have you been seeing friends? gone out to see people or had people round to see you?
0. friends /family invited and visited
 1. some social contacts but friends not invited to house
 2. no social contact with people outside the house
121. Have you had time to do things like watching T.V, going on outings, going to meetings you would like to? Have you had time to do these things every day?
0. has some spare time every day
 1. has spare time some days
 2. has no spare time
122. Have you had any financial problems? Had any extra expenditure or reduction of income, difficulty meeting your bills? Have you found it impossible to pay your bills?
0. no financial problems
 1. extra expenditure or reduction in income which informant finds a strain
 2. severe financial problems, unable to pay the rent/meet debts

123. How have you been getting on at work/with your studies? any difficulty concentrating at work, found work/study too much, or others complaining about your work?
0. no difficulty
 1. some difficulties but no complaints from others
 2. others have complained that informant is not working well
124. Have you had any time off work, doing overtime if it is offered to you? how many days have you had off during last month? were these paid holidays?
0. no time off or paid holidays taken
 1. misses up to 5 days during period or gives up overtime, or regularly late for work
 2. misses 5 consecutive days or more than five days in period, gives up work all together
125. Has your life been disrupted in any way to the point where you left home and went to stay elsewhere? How much time did you spend away from home?
0. informant did not go to stay elsewhere
 1. informant spent at least one night away in period
 2. informant spent more than one night away in period
126. Has there been a lot of friction in the house? couple in the household argued a lot? atmosphere been tense? any member of the household left or threatened to leave?
0. little or no tension
 1. regular argument and friction
 2. constant arguments and/or members of household threatened to leave or actually moved out
127. Has anybody else's life been disrupted in any way? any one in the household taken time off work? Have any of the neighbors or others outside the house been affected?
0. none
 1. other member of household affected
 2. somebody outside household affected, eg. neighbors disturbed at night

If rating is 1 or 2 for any of the above, ask the following questions:

How long since this problem began?

Rating: 1. < 1 week	4. > 1 year
2. > 1 week < 3 months	5. 'always'
3. > 3 months > 1 year	9. not applicable

<u>problem</u>						
128. physical health	1	2	3	4	5	9
129. emotional health	1	2	3	4	5	9
130. social life	1	2	3	4	5	9
131. leisure time	1	2	3	4	5	9
132. disposable income	1	2	3	4	5	9
133. work/study performance	1	2	3	4	5	9
134. time off work/study	1	2	3	4	5	9
135. disrupt. informant life	1	2	3	4	5	9
136. household relationships	1	2	3	4	5	9
137. disrupt.of others' lives	1	2	3	4	5	9

How did you feel about this problem? Were you upset, annoyed, distressed, worried, or disturbed by it?

If problem has been present for at least a year, but informant expresses no distress ask: Have you got used to it?
(if yes, rate 8).

If informant expresses some distress, ask: did you feel you couldn't stand it for much longer? That you would have had to leave home or that it would make you ill? (if yes, rate 2).
(for other expression rate 1).

Rating: 0. none	8. resignation
1. moderate	9. not applicable
2. severe	

<u>problem</u>					
138. physical health	0	1	2	8	9
139. emotional health	0	1	2	8	9
140. social life	0	1	2	8	9
141. leisure time	0	1	2	8	9
142. disposable income	0	1	2	8	9
143. work/educational performance	0	1	2	8	9
144. time off work/study	0	1	2	8	9
145. disruption of informant life	0	1	2	8	9
146. household relationships	0	1	2	8	9
147. disruption of other's lives	0	1	2	8	9

Section 6

Support to informant:

Finally, I would like you to inform me about the kind of help and support you have been getting from friends, relatives and social services over the last 1 month.

In the last 1 month did you see or speak to any of these people on regular basis? Once a week or more?

- | | |
|-------------------------|----------------------|
| 0. no contact | 3. > 3 contacts/week |
| 1. at least one contact | 4. daily |
| 2. once a week | |

Contacts

148. Relatives	0	1	2	3	4
149. friends/neighbors	0	1	2	3	4
150. social worker	0	1	2	3	4
151. community nurse	0	1	2	3	4
152. Mulla	0	1	2	3	4
153. Herbalist	0	1	2	3	4
154. Fortune teller	0	1	2	3	4
155. Zar performer	0	1	2	3	4

Did you see any of the above about the patient and the problem you have described?

Rating: 0. no 1. yes 9. NA

Contact

156. relatives	0	1	9
157. friends/neighbors	0	1	9
158. social services	0	1	9
159. Community nurse	0	1	9
160. Mulla	0	1	9
161. Herbalist	0	1	9
162. Fortune teller	0	1	9
163. Zar performer	0	1	9

Did you have any practical help from relatives in the last month, eg. money, looking after the children, coming to stay or help out, having someone to stay, visiting you or the patient?

(Ask the same question for friends/neighbors, and modify for social services and native healers)

Ratings:

- 0. no practical help
- 1. some practical help
- 2. took over one or more responsibilities
- 9. not applicable

Contact

164. relatives	0	1	2	9
165. friends/neighbors	0	1	2	9
167. social services	0	1	2	9
166. community nurse	0	1	2	9
168. Mulla	0	1	2	9
169. Herbalist	0	1	2	9
170. Fortune teller	0	1	2	9
171. Zar performer	0	1	2	9

Did this practical help make it easier for you to manage?
would you have been able to cope without this help?

Rating:

- 0. no relief
- 2. considerable relief
-could not cope otherwise

- 1. some relief

- 9. not applicable

Contact

172. Relatives	0	1	2	9
173. Friends/neighbors	0	1	2	9
174. social worker	0	1	2	9
175. community nurse	0	1	2	9
176. Mulla	0	1	2	9
177. Herbalist	0	1	2	9
178. Fortune teller	0	1	2	9
179. Zar performer	0	1	2	9

180. What kind of help you felt you needed with the patient,
but was not available to you then?