

Family Involvement in the Treatment of Hospitalised Individuals with Persistent Mental Illness

持續性精神病的住院病人家屬參與之治療計劃

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Abstract

Objectives: To describe a family intervention programme aimed at attracting family members of patients undergoing long-term hospitalisation to take an active interest in the treatment of their relatives, and thus restore hope and optimism to both the patients and their families.

Participants and Methods: Families of patients with persistent schizophrenia were invited to participate in an intervention programme that included a family get-together geared to involve them in patient care. Relatives of 40 long-term patients participated in the event.

Results: Three families who had previously never visited the hospital participated in the event. Among families that did visit, relatives, mainly siblings, came to the hospital for the first time. Four of the 11 patients who had previously never been taken out for a 'vacation' were taken home for a visit following the event. For the whole group of patients, home visits increased by a mean of 24%.

Conclusions: Psychoeducation and additional ongoing activities geared to involve families in the care of their relatives are necessary to maintain contact between patients undergoing long-term hospitalisation and their families.

Key words: Family therapy; Hospitalization; Rehabilitation; Schizophrenia

摘要

目的：描述一個對象為長期住院精神病人的家屬參與的治療計劃，讓家屬對病人治療產生興趣，從而為病人及其家屬重燃希望及正面的情緒。

參與者與方法：邀請持續性精神分裂住院病人的家屬參與治療計劃，包括家人聚首一堂，並一起關顧病人。40位病人的家屬參與此計劃。

結果：有過往從未到訪醫院的三個家庭參與此計劃。曾到訪醫院的家庭中，有家人（主要為兄弟姊妹）屬首次探訪病人。探訪當日後，11位從未外出的病人中，有4位的家屬接病人到家裏作假期活動。整體來說，家訪平均增加了24%。

結論：要維持長期住院病人和家屬之間的關係，精神病教育及有家屬參與的關顧活動相當重要。

關鍵詞：家庭治療、住院、康復、精神分裂

Introduction

Schizophrenia has been described as "an ungraspable,

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deathlike calamity, not only to psychotic patients, but also to their kin".¹ The uncertainty associated with persistent mental illness often leads to unresolved grief associated with ongoing loss, which is consistent with the experience of chronic sorrow.² Schizophrenia thus takes a heavy toll on patients and their families. Aside from emotional, psychological, and financial difficulties, families of patients with schizophrenia often experience guilt, shame, and embarrassment that becomes a heavy burden.

Many studies have investigated the importance of family relationships among individuals with schizophrenia.³⁻⁹ Caring for a relative with schizophrenia is difficult. The term "treatment burden" was first mentioned in 1950.¹⁰ At that time, studies that investigated family burden found that caring

for a relative with mental illness interferes with the daily lives of the families, with their social activities, work attendance, creates a financial burden and affects the relative's capacity to devote time and emotional resources to the patient's siblings and other healthy family members.¹¹ Studies from the 1980s contributed to a broader understanding of the treatment burden on caregivers and families. Gender studies reported that relatives of male patients experience limitations and greater lack of functioning than those of female patients.¹²

Disturbed behaviour is a greater determinant of burden severity than the psychiatric diagnosis.¹³ Moreover, the severity of psychotic symptoms and disability are related to higher levels of family burden.¹⁴

In our department we observed that during the first hospitalisation, family members generally visit the patient, meet with therapists and are involved with the treatment. There is a direct relationship between the length of hospitalisation of the individual with persistent mental illness and the rift created with family members. Among patients with persistent mental illness, we sometimes see a disconnection with the families. The families might lose hope, become angry with the patient, and often prefer to follow the adage "out of sight, out of mind".

Most studies support the idea that family interventions improve the family atmosphere and ease the treatment burden.^{15,16} In order to balance the views of patients and their caregivers, families should be involved in the treatment process and support directed at them should be increased. Studies have investigated potential appropriate approaches to various family interventions, including: counselling, supervision or therapy, while attempting to suit specific treatments to each family according to perceived needs.¹⁷ The literature relates to families with high expressed emotions, high intrusiveness, those that do not accept the illness and believe that with good will, the patient will be able to restore normal functioning.¹⁸ Although in the last 3 decades many studies were performed on this topic, there is still a need to find additional useful methods for involving families in the treatment of their relatives and improve the means to support them. Family support programmes promote understanding of the disease, thereby reducing the intensity of distress they experience and help cope with their relatives' disorders. When families understand the patient's limitations and no longer attach blame, the relationships between all parties tend to improve.¹⁹

What is the role of the therapists in the rift between family members and patients? Mental health caregivers often refrain from involving family members in the treatment of their patients.²⁰ Reasons may include a heavy workload, the feeling that treatment time should be devoted only to the patient,²¹ the perception that the family is responsible for the illness,²² and lack of awareness of the importance of family involvement.

In a study performed in Italy,¹¹ the treatment burden of families of inpatients with anxiety disorders and obsessive disorders was compared with that of families of schizophrenia inpatients. The main difference between families of individuals with schizophrenia and those of

patients with neurotic disorders is the degree of neglect; families of schizophrenia patients tend to reveal more neglect of their healthy family members (e.g. siblings of the patient). Both groups described distress and pain, and the need for more leisure time that is lacking when there is a mentally ill member of the family.

In a different study, Nielsen²³ found that families that could not cope with the changes that occurred in their relatives lost hope and cut themselves off. The department staff often responded with anger towards them, stemming from identification with the patients. These frustrations had the potential to augment antagonism towards the families. To compensate, staff members often try to become a surrogate family.²³

Ethical issues were raised in meetings with the families: Who is the patient? To whom is the therapist loyal when there is conflict of interests? Does the benefit of the patient always come before that of the family? Are there situations where the therapist's close involvement may harm the family or the patient?

In our rehabilitation ward some patients enjoy regular visits, and even go home for weekends, but many others almost never see their families. In the hospital there are various support groups for family members. They include: groups for parents and siblings, long-term groups and short-term focus groups. The family members that do not participate in support groups generally also do not attend meetings with therapists.

Within the framework of the project of quality improvement, the nursing staff had a brain-storming session to find a means of enhancing patients' quality of life. After an in-depth discussion, it was agreed that the most difficult problem was the lack of contact between the patients and their families. Individual therapists related reports from therapy sessions, concerning the distress regarding a longing for their families, and the corresponding difficulties associated with loneliness and lack of contact with loved ones. These problems surfaced daily and were compounded during the holidays. The sense of loneliness experienced by the patients and the decline in family visits go hand in hand with longer hospitalisations. This prompted us to further examine the potential benefits of family interventions. Although much has been written about the importance of family relationships among individuals with schizophrenia and their relatives, the literature on the disconnection, despair and lack of hope among relatives of persons with persistent mental disorder is scarce. The authors describe a family intervention programme to attract family members of patients undergoing long-term hospitalisations to take an active interest in the treatment of their relatives, and thus restore hope and optimism to both parties.

The department is an open ward for patients with persistent mental disorders. Referrals are from active wards, and houses patients who are not ready for discharge into the community, even months after admission. The patients have a structured schedule in the morning, including occupational therapy and group sessions, and free time in the hospital grounds in the afternoons. All patients in the department

voluntarily consented to hospitalisation. Families are welcome to visit, and take patients home for weekends.

Methods

All inpatients in the department (32 men and 8 women; age range, 30-65 years) participated in the event. A total of 25% of the patients had married and had their own families; among these one was still married, and the rest divorced. The remaining 75% had never married. Family members who were potential visitors were generally parents, siblings, or children.

All the patients suffered from schizophrenia, with a predominance of negative symptoms. The average length of hospitalisation was 3 years. During the last year, 21 patients had no overnight 'vacations', among whom 10 had been taken for short 'vacations' (a few hours), and 11 had had none. Seven patients did not even have visits from any relatives. Two patients did not have first-degree relatives living in Israel.

Establishment of Family Group Meetings

It was decided to arrange family get-togethers. The issue was raised during individual therapy sessions with each patient and in group sessions that included patients and staff. Initially, concern was expressed regarding this type of event, but after the subject was worked through in individual therapy sessions, none of the patients objected to inviting their families.

In an effort to develop closer relationships between the patients and their families, meetings with the families were initiated by the staff. The goal of the first in a series of planned activities was to renew the social relationships between the families that had cut off relations with their patient / relative, and strengthen the connection between families who had weak relationships with their hospitalised relatives. This entailed creating emotional experiences, and forming a family member group that would share their experiences of caring for their relative with persistent mental illness. Participation in the group was expected to provide the families with a support system.

The Event

The event was geared to include family members that did not generally visit their relatives in the hospital. Thus, personal face-to-face invitations were available options. Invitations to the meeting were mailed, and telephone calls were made to confirm participation, in an effort to establish personal one-on-one contact. The meeting was scheduled for a Friday, and 20 families attended. The entire department staff including physicians, social workers, occupational therapists, nurses, students performing field work, and volunteers all participated.

The event began with greetings and lectures, followed by community singing led by a volunteer. The patients and their families joined in the singing in a warm and pleasant atmosphere. Both parties then went to activity centres that included: a pet farm (where they cared for pets), an arts and crafts workshop (where they worked together on handicrafts), and a sports centre (where they competed in various games /

sports). The activities lasted about 3 hours, and there was a general feeling that they could have continued longer.

The staff decided to evaluate the success of the project by recording the number of family visits and vacation days per patient before and after the family meeting. Since this was a social event aimed at enhancing quality of patient care rather than a prospective clinical trial, no study protocol was submitted to the Helsinki (Ethics) Committee. The effect of the event was measured by the number of times the patients were taken home on leave, rather than by a structured evaluation of quality of life.

Results

Of the 7 families that previously never visited the hospital, members from 3 of them attended the event. Among families that did visit, there were members who did so for the first time, especially brothers and sisters that had previously left 'this job' to the parents. Of the 11 patients who were previously never taken out on leave, for the first time 4 were taken out after the event. In the year preceding the event, the average number of 'vacation' days per month in the department was 37. In the year following the meeting, the average was 46 (a 24% increase). Most patients mentioned a sense of enjoyment and happiness following the event.

Discussion

The attempt to re-establish family relationships between inpatients with persistent mental illness and their families may reveal complex relationships between the parties.

Atkinson²⁴ suggested that parental loss of a child through schizophrenia leads to a pattern of "chronic grief". The uncertainty associated with persistent mental illness creates a situation that has no foreseeable end to the loss experience, thus there is no prospect for resolution of the situation that is causing the grief. This unresolved grief, compounded by ongoing loss, has been called "delayed or chronic grief", and is consistent with the experience of "chronic sorrow".² Feelings of anger often permeate the experience of "chronic sorrow" for parents of mentally ill adult children, as anger is an integral part of the grieving process.²⁵ Parental anger is often viewed as inappropriate when associated with grief.²⁶ The lack of awareness of the "anger" component in parental sorrow could contribute to adversarial relationships between family members and hospital staff.² Once they despair, there is a danger of "getting stuck". In long-term hospitalisation, chronicity is often accompanied by despair. The patients lose the desire to be discharged and families often 'give up' on the patients; family members often associate the caregiving responsibility and involvement with reactivation of the grieving process.²

The aim of our intervention was to move the families from despair back to life to the stage of acceptance and maintaining relationships. This demands energy and time, as "chronic sorrow" is a normal response to never-ending loss. Sometimes, despite the difficulty it is necessary to

ignore the distress of the families and prioritise on behalf of the patient. When dealing with older patients, sometimes the relationship is with their children. Such 'children' cut themselves off, so that they may establish another life. The difficulty encountered by young men and women when they see their parents hospitalised is understandable; however in our role as caregivers for patients / parents, our primary concern is the welfare of the patient.

"Chronic sorrow" or periodic reactivation of grief may have a healing quality for ongoing loss situations, such as through caring for a mentally ill family member. Awareness that unending caregiving responsibilities may trigger recurrence of grief-related feelings in family members of mentally ill inpatients, helps hospital staff provide appropriate supportive interventions for these families. Ultimately, this can contribute to the well-being of the patients. The caregiver strives to help patients and their families cope with their loss and deal with the illness. By providing a support system for the families and seeking the most appropriate treatment for specific patients, the caregivers hope to avoid despair both among the patients and their relatives. The planned event aimed to bring the patients closer to their families, and the families closer to the staff. An enjoyable programme revealed a different meaning to relationships with the patients. The setting enabled mutual pleasure and satisfaction, rather than the pain and heartbreak that is often involved in caring for a mentally ill relative. Positive pleasant experiences bring the patients, the family, and the staff closer together and foster a desire for more such meetings. It was not plausible to expect one event to make a significant difference to relationships between the families and their hospitalised relatives. Nevertheless, the event we described contributed to increased involvement in the care of corresponding hospitalised relatives, and lead to a significant increase in hospital and home visits, albeit for a limited period.

Additional, ongoing activities geared to involving families in patient care are necessary in order to maintain contact between individuals in long-term hospitalisation and their families. In addition to psychoeducation and family support groups, we scheduled leisure activities such as patient birthday celebrations with family participation. Another option was an exhibition of artwork by patients in the department's studio, that could be open to all families, staff, and the Association of Friends of the Hospital. We believe that social involvement of the families with the patients enhances the involvement of family members in the therapeutic and rehabilitative aspects of patient care.

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