TROUBLESOME CASES IN COMMUNITY CARE

ELIZABETH TUCKER

INTRODUCTION

Throughout the Western world changes in the pattern of care of the mentally ill have resulted in rising first admission rates and falling hospital censuses. These trends result in an increasing number of ex-mental hospital patients in the community. Many individual programs are definitely aimed at preventing hospitalization and shifting the focus of services from the hospital to the community.

Speculation about the effects of this fundamental shift of policy inevitably leads to questions about the extent to which the burden of care is being imposed on the community. Are we making unreasonable demands on the family or the community? Is this modern fashion being exploited by administrators who underestimate the extent of this burden and fail to make proper provisions for treatment and asylum?

Dutchess County in New York State has the doubtful distinction of having for many years the highest mental hospital first admission rates in the state and probably in the country. This county was chosen as the location of a demonstration community psychiatric service based on a regionally decentralized county unit which opened in January, 1960 within the Hudson River State Hospital. The county services and the county unit of the state hospital are closely integrated and share certain psychiatric personnel. Research designed to evaluate the effect of this service included the pilot study here described for investigation of these questions.

METHODS

Other parts of the evaluation studies set up a register of all residents of Dutchess County who had been psychiatric patients since 1955. Those who had been inpatients or day-care patients were interviewed to discover the most disabled. In the summer of 1963, 1,425 such persons under 60 years of age were listed on the register. Approximately 125 were excluded from interview on a random basis for administrative reasons. A random half (648) of the remainder had been scheduled for interviews during the first half of 1963, but only 481 had been interviewed at the time this study was started.

The interviews identified cases of social disability on an objective basis. During the interview, individuals were asked specific questions about their activities during the preceding week; subsequently ratings were made, according to standard rules, on the basis of the factual reports recorded in the interview protocols. A person was classified "disabled" if his protocol failed to show evidence of two hours of work or two hours of a productive hobby on one day, some active recreation, and a period of at least three hours without supervision. Other people who were "very troublesome" were also classified as "disabled." "Very troublesome" behavior includes assaultiveness, inappropriate aggressivesness, suicidal attempts, incontinence, requirement for restraint, or need for restriction from self-harm.

To study the community and family adjustment of the most impaired individuals, "disabled" cases from 481 who had been interviewed prior to the beginning of the study in the middle of 1963 were selected for investigation.

Inpatients and cases who were in family care[1] from the hospital were not included in this investigation. The sample thus selected of the 40 "disabled" individuals under 60 years of age and out of institutions is a little less than a random half of such individuals in a population of about 180,000.

During the summer of 1963 efforts were made to see all of these 40 patients and the people with whom they were living. Two partially structured interviews were devised, one for the patient and one for the relatives. Home visits were made shortly after sending letters. If the patient was the first family member reached, his co-operation for our interviews with other members of his family was sought and usually received.

Successful interviews were achieved in 34 of the 40 cases.

In four cases neither the patient nor a relative could be contacted

to obtain interviews. In two cases the first person reached (one patient and one relative) refused to co-operate and no information was obtained. Distribution by the type and number of informants for each patient is shown below:

TABLE I. NUMBER AND TYPE OF INFORMANTS SEEN FOR 34 CASES STUDIED

Patient only	4
Relative only	1
Patient and 1 relative	24
Patient and 2 relatives	5
Total number of interviews	68
Cases with no informants reached	4
Cases with refusal by individual reached	2

The six patients for whom there were no interviews are of interest. One refusal came from a woman of 59 who felt strongly that she did not wish to discuss her hospital experience, although she was still being followed by a hospital doctor and had recently improved sufficiently to return to caring for her own home. Another refusal was from a 43-year-old man who had been diagnosed as psychoneurotic during a 17-day hospital stay. When visiting his home, the interviewer learned that he was at work, and his wife was extremely hostile to the request for an interview either with her or the patient. One woman was away with her family for the summer. One man of 39, with a diagnosis of schizophrenia and a history of hospitalization before coming to Dutchess County, as well as a 10-month stay in the Hudson River State Hospital, had left the farm where he was employed a week before our interviewer arrived and had not returned. Another man who spent a week in the hospital, presumably for an alcholic problem, agreed to an interview by phone but was never at home at the times he told the interviewer he would be. A 17-year-old boy and his family gave no response to mail or phone or doorbell approaches, and were never reached. Review of the evidence available did not indicate that this was a particularly disabled group.

FINDINGS

Twenty-four were married, 11 single, three separated or divorced, and two widowed.

Twenty-one lived in the city of Poughkeepsie and 19 in other parts of Dutchess County.

Three people had received day-care treatment only. Accumulated time in hospital for the others ranged from two days to 26 years, with a median of two months and nine days. Twenty-six had been hospitalized once, five twice, and six more than twice.

Socio-economic status for the members of the sample appeared to vary considerably, but no systematic measurement was made.

TABLE 2. ASSIGNED DIAGNOSTIC CATEGORIES OF THE "DISABLED" INDIVIDUALS

Diagnosis	*No. of Individuals*
Schizophrenia	9
Psychoneurosis	12
Primary behavior disorder	3
Psychosis with mental deficiency	3
Psychosis (functional), other	3
Psychosis (organic)	6
Convulsive disorder (no psychosis)	1
Day-care only (diagnosis unknown)	3
Total	40

TABLE 3. SEX AND AGE DISTRIBUTION OF THE SAMPLE

	Male	*Female*	*Total*
Under 20	1	1	2
20–29	2	2	4
30–39	6	6	12
40–49	7	2	9
50–59	2	11	13
Total	18	22	40
Successfully interviewed	14	20	34

The interviewers collected information about 34 "disabled" cases regarding employment, services given and received in the home, social and emotional relationships, and community problems.

Employment

Eight males and two females were gainfully employed at the time of the interviews; 18 women not employed had some responsibility for keeping house. Both of the two women employed outside the home were also keeping house.

Fairly obvious explanations were found for the lack of employment in each of the six male cases. One was receiving a veteran's pension for service-connected schizophrenia; another was in jail for assaulting a policeman while under the influence of alcohol; one was receiving Workmens Compensation for injuries which prevented him from working; one considered himself to be incapacitated by severe back pain; one had frequent, severe epileptic seizures; one had recently been laid off a regular job and lied about this to the interviewer—the fact was learned from interviews with his family.

Needs for service from other members of the household were weighed against the services contributed by the "disabled" person to the household. Only one woman was found to demand more services than she contributed; she had undergone spinal surgery several months before our visit and was having difficulty in getting around. Four men demanded more service than they gave at home; three were gainfully employed, and the fourth claimed physical illness.

The impression regarding needs for service from the family in this group is that the demands were minimal. Evidence showed that family members rarely had to provide frequent, special, or time-consuming services for these people because of psychiatric impairment.

Social Relationships

Eleven were described as showing warmth and friendliness and were appreciated as companions, 14 were for the most part withdrawn, and 9 tended to discourage social interaction by their behavior or their directly expressed hostility.

Six people were considered to be having an adverse effect on the emotional well-being of their relatives. This judgment was made primarily on the basis of the relatives' expressed distress rather than on the subject's actions alone. The two men considered to be emotionally destructive had severe alcohol problems, although in neither case was this the primary diagnosis at the time of hospitalization. One of them was separated from his wife and the other was getting along very poorly with his. Neither was psychotic, one having been diagnosed as a psychopathic personality, the other as a reactive depression.

These facts about the 34 interviewed cases give a partial picture of the social burdens the 40 most seriously disabled patients living in the community imposed on it.

The seven most extreme cases of community burden discovered through this three-stage process are described below in more detail. Each of these imposed a specific set of burdens, and it was not found possible to make sensible judgments regarding how much trouble one case was as compared to the others. All seven were judged to be more troublesome than the other 27.

CASE REPORTS

Case 1. A schizophrenic woman said she was having great difficulty running a household with three young children. She said she did housework all day, cleaning and washing, but we learned from her husband that she was completely ineffective. Her husband was living with her despite complete dissolution of the marriage, since he was so concerned about her failure to provide adequate care for the children. He thought she probably ought to be hospitalized again but did not present a plan regarding the children's custody. The investigator's impression was that it would probably be better for all concerned if the woman was hospitalized. This occurred several months later.

Case 2. An alcoholic woman lived with her teen-age son. He had been in the mental hospital repeatedly. After telling the hospital staff that she would take her son out of the hospital and provide a home for him, she then rejected him and returned him to the hospital. This sequence had occurred repeatedly. She was separated from her husband. She was said to have also caused considerable disruption of another son's personal life; he was living with his father's parents. This woman's only hospital diagnosis was alcoholism and psychoneurois-reactive depression. She was judged to be not certifiable at the time of this study.

Case 3. A young woman had been in trouble since leaving the hospital. She had been sent to the hospital for disturbed behavior. Her diagnosis was psychopathic personality. A short time before our investigation she was arrested for assault and was sent to jail. She had been released on probation at the time of our investigation. She was unemployed and lived with her parents; she did some housework at home. Her father gave the impression of a poor adjustment of which the parents were ashamed. It was doubtful that hospitalization at that time would have helped. She could not have been hospitalized against her will. Additonal information was obtained. A year later she had moved from her parents' home to live with some relatives who owned a farm; she was working there and receiving pay and was apparently moderately well adapted.

Case 4. At the time of the study an alcoholic man in his fifties was in prison for assaulting a policeman when intoxicated. He had had a pattern

of alcoholic excesses and practically no work record for a considerable period of time. Between alcoholic bouts this man restituted sufficiently to make him ineligible for psychiatric hospital care.

Case 5. A woman in her fifties had spent over two decades in the hospital and was sent home shortly after the Dutchess County Unit opened; she was in a rehabilitation program there. She lived with her mother and several siblings in a large home in a middle-class neighborhood. Her family complained that she did not fit in with the activities and social visting patterns to which they were accustomed. They also complained that she stayed up late at night and smoked too much; the interviewer suspected that this anxiety was because of uneasiness about the possibility of a fire. They complained that she talked to herself and spent too much time by herself and was inconsiderate of other people's feelings.

Case 6. A partially paralyzed woman in her late fifties lived with her husband. A spinal operation had made it possible for her to walk, but only with a walker. With this instrument she could walk several blocks. The husband had to do all the housework as well as care for her. Her diagnosis had been psychoneurosis. The entire burden on the family was due to the physical disability. She probably could have contributed more to the housework than she did, but the husband did not make this complaint.

Case 7. A very obese woman in her thirties, living with her husband on welfare income, had a mild orthopedic disability for which she refused rehabilitation opportunities. At an earlier period a diagnosis of psychosis with mental deficiency had been made. She lived a childlike, passive-dependent life, spending practically all her time either sitting on a couch or in bed. She was completely dependent on her husband for all features of housekeeping. The husband had no complaints about this, although he did tease his wife, in a good-natured way, about her failure to reduce her weight.

DISCUSSION

Interpretations

By starting with a register of all patients who had received inpatient or day hospital treatment since 1955, and having screened half these patients and former patients in terms of an objective index of disability, it was possible to identify 40 in the community who had objective evidence of disability. Investigation of 34 of these individuals revealed no example of a chronic psychotic person leading a regressed and solitary backward type of existence, although fears have been expressed that such individuals might appear in a setting where community care is extensively offered. The most severe social burdens found were of a variety which might well exist among other members of the popula-

tion who have not had psychiatric treatment. Only a few were appropriate for mental hospital care, and three were hospitalized within several months of the study.

From these findings it may be inferred that this pattern of community care of mental patients, using the mental hospital for acute episodes of decompensation, does not impose a large number of very severe burdens on the community. The prevalence of problems as severe as the seven most severe described is about 10 per 100,000 general population. The varieties of severe burdens overlap the type of social and family problems found among people who had never had psychiatric treatment. Some of the cases of severe burden are not eligible for mental hospital care, and others would not be expected to benefit from it.

The low frequency of severe burdens among psychotic people living in the community is presumably due to the ease with which readmission to the hospital can be arranged. Many handicapped people are currently released from the hospital, but this policy can be expected to impose few burdens of long duration only if the hospital stands ready to accept the patient back at the first signs that trouble is becoming excessive. The Dutchess County Unit of Hudson River State Hospital has such a policy.

Limitations

While the above conclusions can be drawn from this pilot study, it was not comprehensive in that this study made no effort to discover whether suicides, personal assaults, or serious accidents had become more common as a result of the changed pattern of care. Also the search for chronic burdens was not as complete as might be wished. In 1963, when the study was done, the annual interviewing methods were still loose enough so that 15 per cent of register members under the age of 60 were not interviewed when scheduled. Perhaps more severe cases of disability, imposing more severe burdens, existed in the 15 per cent not interviewed. However, subsequent experience in making annual survey interviewing rates more complete suggests that difficult-to-find subjects are mostly very active, well-organized people who are rarely home when the interviewers look for them. Furthermore, subsequent annual interviewing of all former hospital cases has yet to provide a report of a case spending time in a room with no activity for protracted periods of time, although the levels of disabilities reported in this paper continue to be reported.

Needs for Future Research

Further delineation of the kinds of community problems arising in various types of community care services are indicated. Studies of the frequency of similar kinds of problems among people who have never been in a mental hospital would also be useful. Studying the frequency of such problems among people living in densely populated urban areas, or areas where integration of psychiatric services does not exist, could broaden our understanding of the intensity, organization, and distribution of services needed to meet the mental health needs of various areas. A controlled intensification of services to the group identified in the present study would help to find out what efforts can be effective in alleviating the problem situations found in this population.

SUMMARY

A pilot study measured the frequency and nature of troublesome cases existing in a population receiving a community care type of psychiatric service. The entire population of formerly hospitalized persons was screened according to objective criteria of level of function. A sample of those with objective evidence of severe impairment of personal or social functioning was intensively studied by interviews with both the former patients and their relatives. The problems found in this population group of 34 were rarely due to certifiable psychiatric disorders and many of the most disabled individuals were contributing in significant ways to their families and households. This finding is attributed to the ease of readmission when difficulties arise. "Easy in" and "easy out" are complimentary parts of a revolving-door pattern of hospital use for acute episodes in chronic or recurrent disorders.

REFERENCE

[1] In New York State, "family care" is an administrative device for placing handicapped psychiatric patients in private homes with a weekly compensation to the family for room and board. In practice in this area certain people with large houses specialize in this function, and have 10–12 patients living with them continuously. Since this is not an example of burden on the community, such patients were not considered.

ACKNOWLEDGEMENTS

This work was supported in part by a National Institute of Mental Health Training Grant Number 2M5878C-8 and by the Grant Foundation. The work was done in co-operation with the Milbank Memorial Fund, Hudson River State Hospital, and Columbia University, College of Physicians and Surgeons, Department of Psychiatry. The author wishes to acknowledge her great appreciation of the contributions made to this study by Miss Dorothy Parkel who carried out the greatest part of the interviewing and made numerous constructive comments and suggestions during the investigation.