

OBJECTIVE APPRAISAL OF DETERIORATION IN A GROUP OF LONG-STAY HOSPITAL PATIENTS*

ERNEST M. GRUENBERG, M.D., RICHARD V. KASIUS AND
MATTHEW HUXLEY¹

VARIOUS programs for the rehabilitation of chronic mental hospital patients have been initiated throughout the history of mental hospitals, and in reporting their experiences with these programs each psychiatrist has employed whatever data he could muster to evaluate the effectiveness of his rehabilitation program. In recent years the amount of effort which has gone into gathering data to objectify the evaluation of these programs has increased markedly, although the amount of manpower devoted to evaluation of pilot programs never approaches the amount of manpower devoted to the rehabilitation program itself.

A few years ago the authors, at the Milbank Memorial Fund, went into a partnership with Dr. Robert C. Hunt and Dr. C. L. Bennett at the Hudson River State Hospital in Poughkeepsie, New York. Dr. Hunt wanted to experiment with the creation of a unit within the 5,000-bed Hudson River State Hospital which would be exclusively and comprehensively concerned with meeting the needs of psychiatric patients from the hospital's immediate surroundings, namely, with patients from Dutchess County, New York. He identified a pair of buildings and an appropriate staff for this purpose and gave this Dutchess County service the assignment of taking care of all Dutchess County patients needing services from the hospital, whether these services were hospital, day hospital, aftercare, pre-care or consultation services. Dr. Bennett participated in the panel on Community Mental Health at The Third World Congress of Psychiatry, held in Canada in 1961, and described this serv-

* Paper presented at The Third World Congress of Psychiatry, June 4-10, 1961, Montreal, Canada.

¹ Milbank Memorial Fund, New York, N. Y.

ice in greater detail. Our function was to evaluate the effects on the health of patients.

At this writing we are conducting a number of evaluative studies which will be reported on at a later date. This paper deals with the methods we are using to evaluate the hypothesis that the long-stay patients from the Dutchess County unit will improve in social functioning more than they would have if they had remained in the various services of the hospital where they were in 1959, before the unit was established.

METHOD

We assumed that a control group could be identified which, during the years of the study, would change in the same way and at the same rate that the Dutchess County patients would have. This control group was selected by going to the wards of the hospital where the Dutchess County patients were in 1959 and selecting the non-Dutchess County patient nearest in age to each Dutchess County patient. This automatically matched the groups for age, sex and ward.

We assumed that one week of functioning, observed every six months, would be an adequate sample to reflect the changes we were interested in.

We then developed a method to obtain in a standardized, consistent way, concrete information regarding each patient's social functioning.

In the exploratory phases we interviewed randomly selected staff members of the hospital about the behavior of particular patients on their wards. The patients about whom we inquired were also a random selection from ward lists.

We asked each staff member to describe the patient's behavior for the few days previous. We probed three general areas:

1. What kind of useful things the patient had been doing.
2. What evidence there was that the patient had been taking care of himself.
3. What kind of trouble the patient was, either because help

in daily living had to be provided or because the patient was socially disturbed.

We asked frequently whether the staff member felt he would always know about each of these areas.

This process gave us some important information. It taught us a lot about the hospital and its employees. It taught us their language, and gave us a basis for estimating what the staff could reasonably be asked to do, and what would be resented or regarded as unreasonable or unfair.

From this experience we made a draft questionnaire for attendants and/or nurses to fill out on another random list of patients. This pre-test was followed by interviews, after which instruction sheets were prepared.

It is important to recognize that in a large hospital no one really knows the details of any patient's activities over a long time span. However, this fact can usually be discounted because patients become fairly stereotyped in their behavior and change little from day to day, from week to week, and from month to month. But in this type of study where we are using a pre-selected week as a sample of functioning and are looking for change, it is important to get an accurate statement of the patient's behavior on each day rather than a generalization of what he "usually" does or can be expected to do.

In particular, each of the three shifts knows little of what goes on during the other shifts, so that an around-the-clock picture requires information from at least three informants. Furthermore, no staff member ever works seven consecutive days, so each day must be handled independently. Hence, for a week of observation of one patient, 21 separate inquiries must be made, one for each of three shifts for seven days. On the basis of the preliminary interviews, we made up three questionnaires, one for each shift. Some questions are appropriate for all shifts, some for only one shift. Taken all together the questionnaires cover information on the topics listed in Table 1.

On each topic the informant is asked to check a statement

TABLE 1. AREAS OF PATIENT BEHAVIOR
COVERED IN SURVEY QUESTIONNAIRE

<i>Disturbed Behavior</i>	<i>Socially Integrated Behavior</i>
1. Danger of Self-damage	1. Being Away From the Ward
2. Self-destructive Acts	2. Making Money
3. Control of Physical Movement	3. Work Assignment
4. Disturbance	4. O.T. (Occupational Therapy)
5. Meals	5. Reading or Writing
6. Soiling	6. Recreation
7. Speaking	7. Having Money
8. Arising and Dressing	
9. Going to Bed	

which is true. To illustrate the form of the questions, we have reproduced the last page of the Day Shift Questionnaire. (See Table 2.)

The statements are lined up on the left side. The informant is asked to check one box in each group of statements. Each statement has a brief abbreviation of the statement provided next to it so that the attendant is saved the trouble of reading the whole statement each time he fills out a form. When experienced, the attendant can fill out a form in less than two minutes—they quickly memorize the questions and know which box they wish to check. They appreciate the ease of recording their answers. They are a conscientious corps of civil servants, but some of them find writing awkward and slow. This does not mean that they are non-verbal; they enjoy discussions regarding the exact meaning of each word. Please note that they are *not* asked to say which is the best description of the patient, but are asked to record what in everyday language are called “facts.” If none of the alternatives offered fits the facts, they are asked to make a note or call the office to explain. They have done so, and we have learned thus of alternatives we had not visualized and have consequently revised some questions.

We believe it is vital to read these questionnaires shortly after they have been filled out. When inconsistencies or gaps

K:	READING, WRITING	
	The patient spent more than 1 hour reading and/or writing on this shift	MORE THAN 1 HOUR <input type="checkbox"/> 1
	The patient spent some time looking at a book, magazine, newspaper or letters, or did some writing	SOME <input type="checkbox"/> 2
	The patient neither read nor wrote at all	NONE <input type="checkbox"/> 3
L:	RECREATION (in presence of Ward Staff)	
	The patient took active part in a game, dance or other recreation on this shift	ACTIVE <input type="checkbox"/> 1
	The patient was present at a recreational affair, watched a game or TV for more than one hour	PASSIVE MORE THAN 1 HOUR <input type="checkbox"/> 2
	The patient paid some attention to some recreational affair, a game or a TV show for less than one hour	PASSIVE LESS THAN 1 HOUR <input type="checkbox"/> 3
	The patient gave no attention at any time to any game, recreational affair or TV show	NONE <input type="checkbox"/> 4
M:	MONEY	<small>(See Instruction Sheet)</small>
	Cash or card deposited by patient in Ward Office at patient's own request for safe-keeping is still in patient's charge, and you should mark "CASH" or "CARD ONLY."	
	The patient had some spending money today which he took complete charge of	CASH <input type="checkbox"/> 1
	The patient had no money but took complete charge of a store card	CARD ONLY <input type="checkbox"/> 2
	The patient had money and/or a store card which the Staff held for him so as to prevent loss or foolish spending	HELD FOR PATIENT <input type="checkbox"/> 3
	The patient had no money for personal expenses	NO MONEY <input type="checkbox"/> 4
N:	SOILING	
	The patient soiled one or more times on this shift	SOILED <input type="checkbox"/> 3
	The patient was escorted once or more to toilet but did not soil	ESCORTED DID NOT SOIL <input type="checkbox"/> 2
	The patient was not observed to soil at any time and was not escorted to toilet	NO HELP <input type="checkbox"/> 1
O:	SPEAKING	<small>(See Instruction Sheet)</small>
	This question is not restricted to talk between patient and Staff. Record whether the patient spoke with anyone: other patients, visitors as well as staff. However, if patient spoke only to self and was not responsive to others, check DID NOT SPEAK.	
	The patient did not speak on this shift	DID NOT SPEAK <input type="checkbox"/> 3
	The patient spoke only when spoken to	RESPONDED ONLY <input type="checkbox"/> 2
	The patient spoke at least once before being spoken to	INITIATED CONVERSATION <input type="checkbox"/> 1

Table 2. Sample page from survey questionnaire

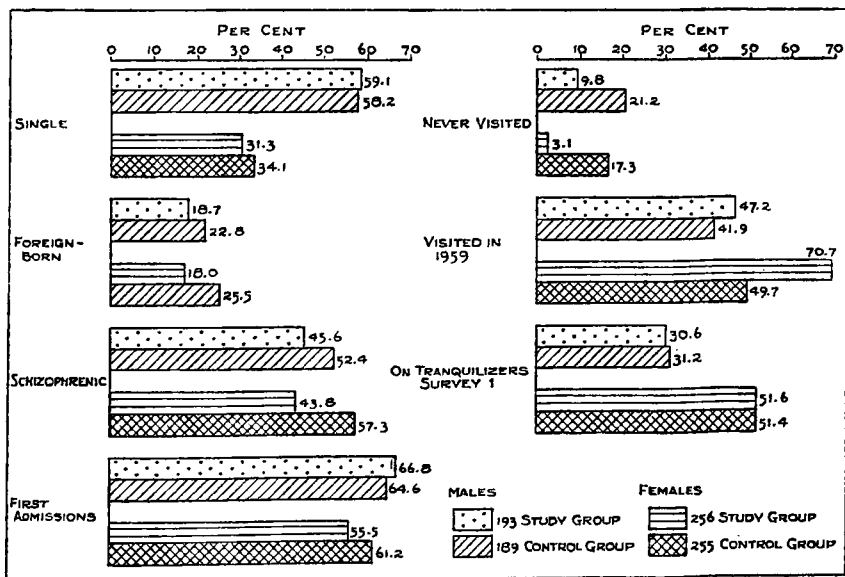
appear, we get in touch with our informants the next time they appear on duty. We like, when time permits, to go to the ward and discuss the problems with the attendants. In that way we are kept in close touch with them. The midnight to dawn shift particularly appreciates this attention. It is elementary to say

that filling out forms is tedious and that it is human to become careless in time unless the work makes a difference. Of course the ward staffs have no reason to think these forms are important if the research staff does not. It is also obvious that the research staff's behavior tells more than their words do how they feel regarding the importance of accuracy. But obvious as these things may be, it is *not* obvious to research workers that they should get out of bed and visit the wards between 1:00 A.M. and 2:00 A.M., but we do it—and there is no question in our minds that doing it tells the whole hospital more about our viewpoint than anything else we say or do.

EARLY RESULTS

The results of a comparison between the Dutchess County patients and the control patients on certain personal and hospital characteristics are given in Fig. 1. There was satisfactory agreement between the two groups of male patients in marital status, foreign birth, per cent schizophrenic, recent visitors, first admissions, and use of tranquilizers. Only in number of

Fig. 1. Comparison of study and control patients by selected personal and hospital characteristics.



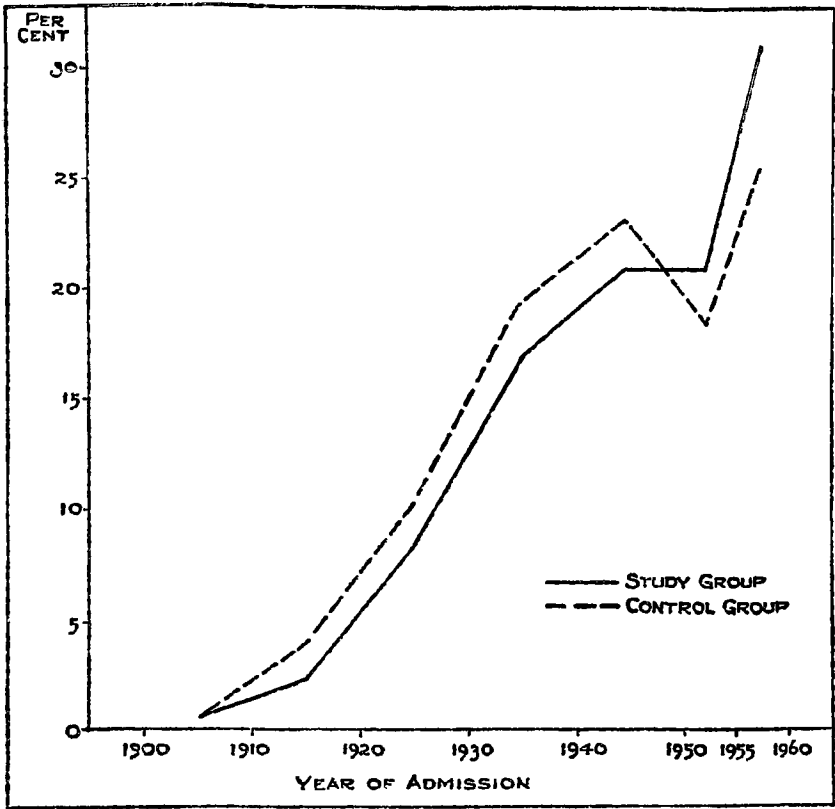


Fig. 2. Distribution of study and control patients by year of admission.

patients never visited, which was significantly greater in the control group, was any difference noted for the male patients. The two groups of female patients differed substantially. The Dutchess County women were less frequently schizophrenic, less frequently foreign born, had less frequently never been visited, and had more frequently been recently visited than the controls. These discrepancies between the females in the study and control groups are obviously disturbing and, in looking back, might have been avoided. However, their effect upon the evaluation can be minimized by sub-classification of the population during the analysis and by studying the influence of these characteristics upon the pertinent variables of the evaluation.

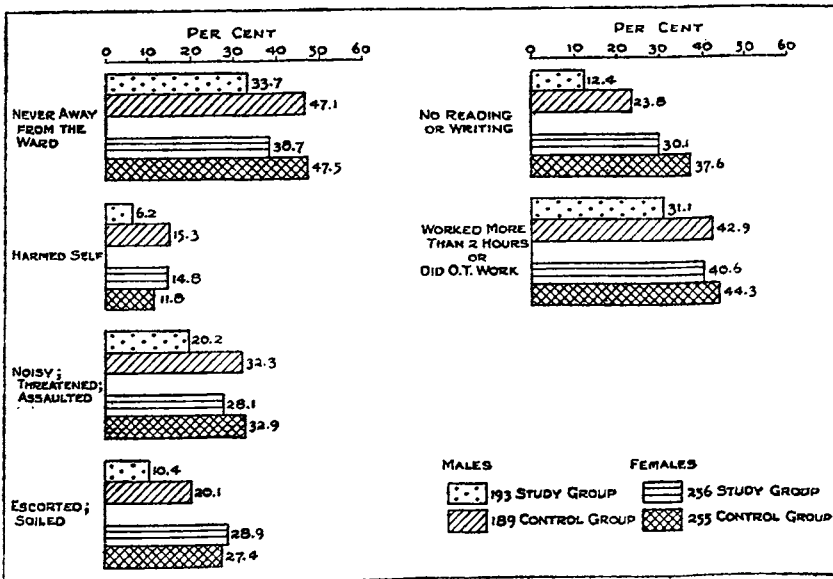
Figure 2 compares the year of admission of the Dutchess

County long-stay patients with that of their controls. The study group had a larger proportion admitted since 1950 than did the control group. A survey of the Dutchess County patients and their non-Dutchess controls, using the questionnaires, was conducted in December, 1959 before the special Dutchess County unit was opened.

The purpose of this survey was to establish a baseline from which subsequent changes could be measured. Further surveys were made in June, 1960 and January, 1961, after the unit was established, and additional surveys are planned at six-and-a-half-month intervals during the five-year observation period.

Comparison of the observations from the first survey on the study and control patients provides additional information on the comparability of the two groups (Fig. 3). Agreement between the two female populations was good on all questions except that the non-Dutchess County patients had a significantly higher percentage who were never away from the ward during the survey week than did the Dutchess County group.

Fig. 3. Comparison of study and control patients on selected questions on Survey 1.



Among the males, there were several areas of behavior in which the two groups appeared to differ. The non-Dutchess County male patients included a significantly larger number reported as never away from the ward during the survey week, as harming themselves, as disturbed, as soiling or needing to be escorted to the toilet, as doing no reading or writing and, in areas of social abilities, as working more than two hours on one day or doing O.T. work. In general, it appears that the non-Dutchess County male patients might be considered sicker or more deteriorated than their Dutchess County counterparts.

It may be of interest to note the prevalence of certain types of disabling behavior during one week in a long-stay hospital population of this kind. (The figures quoted are for the study and control groups combined.)

	<i>Per Cent</i>
Never Away From the Ward	42
Considered Suicidal or Self-destructive	8
Harmed Self	12
Patient Was Held, Restricted or Restrained	21
Threatened or Assaulted	5
Resisted at Meals	2
Soiled	12
Did Not Speak	1
Resisted Getting Up	2
Resisted Going to Bed	2

The prevalence of some behavior suggestive of social abilities is as follows:

	<i>Per Cent</i>
Earned Money	8
Worked More Than 2 Hours at Least Once	30
Did O.T. Work	20
Worked More Than 2 Hours and/or Did O.T. Work	40
Read or Wrote More Than 1 Hour	28
Participated in Active Recreation	20
Away From Ward More Than 3 Hours	30

It has seemed worthwhile to combine the observations on the various questions for each patient in order to develop what might be called an index of deterioration. This procedure has yielded a five-category classification of patients. The classification was made by scoring the patient on two categories of questions, one relating to disabling behavior and the second referring to positive social behavior. On the first set of questions the patient was given a score of 0 if he was reported as showing any extreme behavior during the survey, a score of 1 if moderately disturbed behavior was reported, and a score of 2 if no disturbed behavior was reported. Similarly, on the second group of questions a score of 0 meant that no positive social activity was observed, a score of 1 represented some social activity, and patients getting away from the ward, going to work or O.T., and actively participating in recreation were given a score of 2. The two scores were added, yielding the five categories represented by scores from 0, the most disabled patients, to 4, the least disabled.

The classification of patients on this basis, on the first survey (Table 3) showed the study and control groups to be in

Table 3. Per cent of patients at each level of deterioration on first survey in study and control groups by sex.*

LEVEL	CRITERIA		ALL PATIENTS	MALES		FEMALES	
	Disturbed Behavior	Integrated Behavior		Study	Control	Study	Control
Number of Patients			893	193	189	256	255
1. Severe	Extreme	None	4.0	0.5	3.2	4.7	6.7
2. Moderate	Moderate	None	21.1	17.1	21.7	23.8	20.8
	Extreme	Some					
3. Slight	None	None	27.5	22.8	30.2	27.0	29.8
	Moderate	Some					
4. Minimal	Extreme	Active	29.3	36.8	33.3	25.4	24.7
	None	Some					
5. None	Moderate	Active	10.1	9.3	8.5	10.9	11.0
	None	Active					
Unclassified ¹			8.0	13.5	3.2	8.2	7.1

* N. B. This table includes some patients whose questionnaires had occasional missing items; subsequent analysis will take account of these omissions.

¹ These patients were not on their usual ward during the survey; most were on home visit or extra-mural care.

good agreement with respect to this index. There were differences, however, by sex. The female patients included relatively larger numbers in the most disabled category (5-6 per cent) as compared to about 2 per cent of the male patients.

The evaluation of the hypothesis that patients in the special unit will function at a higher level and be less deteriorated than if they had not had the unit's services will be based primarily on study of the changes in patient behavior as reported on the questionnaire. For any area of behavior covered by the questionnaire, patients reported as showing any amount of disturbed behavior in that area on the initial survey can be identified and followed on the subsequent surveys to see if there was improvement, worsening, or no change in such behavior. If the unit does produce an effect upon the patients exposed to its services, we should expect a significantly greater number of patients in the unit to improve than would be observed among the control group. Such an analysis may be made for any desired sub-group of the study population based on, for example, length of stay in the hospital, psychiatric diagnosis, age, use of drugs, etc. In addition, the index of deterioration, or a similar summarizing index, may be utilized to determine whether or not there are differences between the study and control patients in the amount of movement up or down the scale of deterioration on the follow-up surveys. Analyses such as these, and undoubtedly others more specialized and detailed, should provide a basis for estimating the success of the facility in retarding or reversing the course of deterioration in this population of long-stay patients.