

FOLLOW-UP STUDY OF CHRONICALLY ILL PATIENTS DISCHARGED FROM HOSPITAL*

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LONG-TERM illness tests severely the ability of patients and families to look after themselves and of communities to supply the necessary therapeutic and supportive services. Something is known about how patients are cared for in hospitals but much less about how they fare when they are discharged, often to fend for themselves. In order to gain some insight into the nature and magnitude of this problem a study was made of 82 patients before and after discharge from the ward services of three general hospitals in the Boston Metropolitan Area.

The selection of cases and their medical appraisal were entrusted to a resident or a visiting physician. Patients were chosen from one of three categories of illness of specified severity as follows: (a) heart disease with a maximum functional capacity of II, or a maximum therapeutic classification of C§[1]; (b) rheumatoid arthritis sufficiently disabling to make it difficult or impossible for the patient to pursue the normal activities of the patient's age, sex, and physical development [2]; and (c) diabetes requiring at least 30 units of insulin a day for its control. Patients who fell into these three categories of illness were selected in the order in which they were discharged until the monthly quota for each hospital was met. To make follow-up easier, only persons who lived within the limits of the Metropolitan Area were included.

At the time of discharge from hospital, each patient was evaluated by the study physician who completed a schedule which, in addition to the usual personal and medical data, included an estimate of the patient's disability in terms of his capacity to work or carry out the activities of daily living; a description of medical and allied services recommended for a period of 3 months following discharge; and a list of referrals made, specifying the agencies involved. An important stipulation was that the study physician discuss fully with each patient the recommendations for care

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§Patients with heart disease resulting in at least one or more untoward symptoms on ordinary activity or requiring at least moderate restriction of activity by way of treatment.

to be received following discharge from hospital. Patients were told to expect a visit by a social worker in about 3 months. They were not told about the nature of the visit or the purpose of the study.

Follow-up visits were made by students of social work who were carefully prepared for their task. A highly qualified medical social worker assisted in orienting the students, supervised their work and carried out some of the interviewing. The interviewer made a careful appraisal of the current situation of each patient, reconstructed the course of events since discharge from hospital, and determined the extent to which the physician's recommendations were complied with and the reasons for non-compliance. Patients were asked to comment about the care they had received and to point out services that they desired but could not obtain.

It was originally planned to interview the patients 3 months following discharge from hospital. For various reasons it was not possible to maintain this uniformity in the period of observation which, in fact, ranged between 7 days (in the case of a patient who died) and 163 days, with an average of 95.7 days. A little more than half the cases were observed for 90 days or more, and 93 per cent were observed for at least 60 days.

FINDINGS

The patients selected for study

Some characteristics of the patients, noted at the time of discharge, are shown in Table 1. As might have been expected, this was a group of elderly men and women who generally had limited educational and financial resources. The precariousness of their social and economic position is indicated by the fact that, prior to hospitalization, almost half were unmarried, widowed, divorced, or separated; a little more than a fifth lived alone or with unrelated persons; and more than a third were on relief. That, at the time of discharge from hospital, more than half were either completely disabled or had some limitation in their capacity to carry out the ordinary activities of daily living, demonstrates the extent of their physical handicap.

The great majority of patients were included in the study because they had heart disease. Relatively few were chosen because they had diabetes (16 per cent) or rheumatoid arthritis (7 per cent). In keeping with the criteria for selection, the disease was rated 'moderately severe' in 56 per cent and severe in 42 per cent of cases. The index disease was, in most instances, only one out of several which afflicted the patient. Taken all together, there was a remarkable preponderance of diseases of the circulatory system which, in one form or other, were present in 90 per cent of patients. Diabetes, the next most frequent diagnosis, was reported in 38 per cent of cases. Third in frequency was gastrointestinal diseases and diseases of bones and organs of movement (including rheumatoid arthritis) each of which occurred in 18 per cent of patients.

TABLE 1. SOME CHARACTERISTICS OF THE PATIENTS STUDIED AS RECORDED AT THE TIME OF DISCHARGE

Number of patients	82	Living with family before admission to hospital	76%
Males	50%	Unemployed or not in labour force before admission	29%
Average age	61.4 years	Fully or partially able to work	13%
65 years or older	38%	Completely dependent or only with limited ability to carry out the activities of daily living	54%
Married	54%		
Completed high school	28%		
Average family income	\$2751		
Receiving public assistance	35%		

Consequence of illness

The consequences of illness for this group of patients were notably grave. During an average interval of 97 days following discharge, 8 patients (10 per cent) died. Some notion of the progress or deterioration of those who survived may be obtained from estimates of disability made by the interviewer as well as from reports concerning their ability to hold gainful employment. Assuming that the ratings of disability made by the hospital physician and the interviewer are roughly comparable, it would seem that, by the time the interview was made, there had been an increase in patients at both ends of the range, with more persons fully disabled and also more persons with some ability to work than had been estimated at discharge. But the generally persistent nature of the individual patient's handicap is demonstrated by the fact that, during the same period of time, of those who were discharged with some disability, 56 per cent remained the same or became worse. Of those who were discharged unable to work about a third regained some ability to work but only 3 per cent were fully reabled (Table 2). Of male patients who had been employed previous to the last hospitalization more than half (58 per cent) were unemployed when interviewed. Perhaps because of the relative flexibility of their household duties, or the comparatively sheltered and less strenuous nature of their occupation, proportionately more females had regained their ability to work, for at least part of the day, at the time of the interview (Table 3).

TABLE 2. SEVERITY OF DISABILITY AT THE TIME OF DISCHARGE AND AT THE TIME OF THE INTERVIEW FOR THOSE WHO SURVIVED THE PERIOD OF OBSERVATION

Disability at discharge	Disability at interview (No. and %)					Total at discharge
	A	B	C	D	E	
A	2 (2.7%)	—	—	—	—	2 (2.7%)
B	—	5 (6.8%)	2 (2.7%)	1 (1.4%)	1 (1.4%)	9 (12.3)%
C	—	10 (13.7%)	7 (9.6%)	5 (6.8%)	2 (2.7%)	24 (32.9)%
D	2 (2.7%)	10 (13.7%)	7 (9.6%)	9 (12.3%)	5 (6.8%)	33 (45.2%)
E	—	—	1 (1.4%)	1 (1.4%)	3 (4.1%)	5 (6.8%)
Total at interview	4 (5.5%)	25 (34.2%)	17 (23.3%)	16 (21.9%)	11 (15.0%)	73 (99.9%*)

Disability ratings: A. Unlimited ability to work at usual occupation.
 B. Limited ability to work at usual or changed occupation.
 C. Able to carry out activities of daily living but unable to work or adjust independently.
 D. Limited ability for activities of daily living.
 E. Complete dependence—unable to carry out any activities of daily living.

*Excludes one case on which information is not complete.

TABLE 3. OCCUPATIONAL STATUS AT THE TIME OF THE FOLLOW-UP VISIT OF THOSE WHO WERE WORKING WITHIN THREE MONTHS PRIOR TO ADMISSION, ACCORDING TO SEX

Status at interview	Males		Females	
	No.	%	No.	%
All persons	19	100	21	100
Employed at same occupation	5	26	14	66
Employed at different or modified occupation	3	16	1	5
Unemployed	11	58	6	29

These data seem to indicate that in this group of rather elderly and often disabled patients, illness is liable to result in prolonged or perhaps permanent loss of employment, with the hardships which this often entails.

Care and supervision following discharge

In most instances, the patient's family assumes the immediate responsibility for providing the daily attention that the chronically ill person needs. This was true even in this group of patients, many of whom had rather tenuous family ties. During the period of study, 78 per cent of patients lived with, or were supervised by, one or more members of a stable family unit, either continuously or with interruptions for institutional care. There was, nevertheless, a fairly large proportion (22 per cent) of patients who lived alone or with unrelated persons or were cared for in an institution apparently without appreciable family interest or supervision. At the time of the interview, daily help, in almost all instances from members of the family, was available in 69 per cent of patients. Other sources of help (neighbors, community agencies) were trivial by comparison. A small but important percentage of patients (9 per cent) had very little or no help available to them. The remainder were cared for in an institution.

The crucial part played by institutions in caring for many chronically ill patients has already become apparent from the foregoing remarks. During this short period of observation, almost half the patients were re-admitted to some kind of institution including general hospitals, chronic disease hospitals and nursing homes (Table 4).

TABLE 4. UTILIZATION OF INSTITUTIONAL SERVICES DURING THE TIME PERIOD BETWEEN DISCHARGE AND THE FOLLOW-UP VISIT, BY TYPE OF INSTITUTION

Use of services	Type of institution		
	All	General hospitals	Other institutions
No. of persons observed	81*	81	81
Institutionalized	48%†	27%	25%
Institutional days	1436	482	954
Days per person	18	6	12
Days per person institutionalized	37	22	48

*Excludes one patient about whom information was incomplete.

†Persons who were admitted to more than one type of institution are counted only once in the total.

The average duration of institutional residence was 18 days per patient and 37 days per patient institutionalized. In the aggregate, almost a fifth of all post-discharge days were spent in an institution. Persons who were not married or did not live with members of their family were more often admitted to hospitals or other institutions and remained there for longer periods of time (Table 5). This is consistent with the usual finding that the need for institutional care arises partly from a deficiency in family care and supervision.

Confirming evidence of the large amount of hospital care required by this group of patients may be obtained by examining the number of times the patient had been admitted to the same hospital during the 5 years previous to the current admission. The number of previous hospitalizations ranged from 0 to a maximum of 34 for one diabetic patient who was repeatedly admitted for the treatment of acute complications.

TABLE 5. UTILIZATION OF INSTITUTIONAL SERVICES DURING THE TIME PERIOD BETWEEN DISCHARGE AND THE FOLLOW-UP VISIT, BY LIVING ARRANGEMENTS BEFORE ADMISSION AND BY MARITAL STATUS

	Living arrangements		Marital status	
	With family	Alone or with unrelated person	Married	Other
No. of persons observed	62	18	43	37
Readmitted to general hospital	18%	33%	28%	22%
Admitted to other institutions	23%	56%	9%	46%
General hospital days per person hospitalized*	29	36	22	25
Other institutional days per person institutionalized	31	35	14	54

*Excludes one patient for whom length of stay was not reported.

A little less than half (45 per cent) of the patients had not been admitted to the same hospital during the preceding 5-year period; 20 per cent had been admitted once, 11 per cent twice and 24 per cent three times or more. There was an average of 1.56 hospitalizations per person and 2.86 admissions per person hospitalized.

As shown in Table 6, the patients in this study made heavy demands upon the care-taker agencies or facilities in the community. Only 5 per cent of patients did not use

TABLE 6. PERCENTAGE OF PERSONS WHO UTILIZED EACH OF VARIOUS COMMUNITY AGENCIES ONE OR MORE TIMES DURING THE TIME PERIOD BETWEEN DISCHARGE AND INTERVIEW

Community agency or type of service	%	Community agency or type of service	%
None	5	Nursing home, custodial facility	20
Outpatient clinic	62	Visiting nurse service	16
Private physician	33	Social service	39
Home care program	7	Public welfare	15
General hospital	27	Other	7
Chronic disease hospital	11		

any of the agencies listed. In addition to the high level of institutional use which has already been noted, two findings deserve further comment: the large extent to which the ambulatory care of the post-hospital patient involves the outpatient clinic; and, in spite of the severity of the physical and social handicaps which the patients suffered, the relatively infrequent use of social work and visiting nurse services and of organised home care programs.

Services recommended and compliance with medical recommendations

Table 7 shows the proportion of patients for whom specified recommendations were made by a physician either at the time of discharge or during the interval since discharge. Also shown is the proportion of patients who did not comply with one or more of the recommendations in each category.

With respect to the recommendations for care, the predominant impression is that patients are discharged from hospital still in need of a great deal of continuing care and supervision requiring, essentially, that the patient adapt to a new and greatly restricted mode of living. All but one patient required medical supervision and some alteration

TABLE 7. PERCENTAGE OF PERSONS FOR WHOM SPECIFIED RECOMMENDATIONS WERE MADE AND PERCENTAGE OF PERSONS WHO DID NOT COMPLY

Services	% with recommendation*	% not complying†
Medical supervision	99	21
Outpatient department	83	22
Home visits	32	4
Office visits	11	11
Regimen	99	33
Dietary modification	90	22
Oral medication	77	13
Self-administered injection	27	9
Regulation of daily activities	68	11
Nursing service	36	17
Injection	28	4
Dressings	6	40
Bedside care and observation	2	‡
Rehabilitation services	24	50
Physical therapy	12	40
Dental services	4	0
Social services	45	22
Institutional care	34	14

*% of total number of patients.

†% of patients for whom service was recommended.

‡Bedside nursing care was recommended for only one person who did not receive such care. Observation was recommended for two persons, one of whom did not receive this service.

in daily regimen. Plans for medical supervision envisaged outpatient clinic care for as many as 83 per cent, home visits for 32 per cent and office visits for 11 per cent of cases.

When details of regimen to be pursued by the patient are examined, it appears that for 90 per cent of patients there was a recommendation for some form of dietary modification in many cases of a fairly restrictive kind. Oral medication was recommended for 77 per cent of patients, and self-administered injections were recommended for 27 per cent. Instruction concerning the regulation of daily activities (exercise, rest, etc.) were given to 68 per cent of patients.

Nursing service at home was prescribed for 36 per cent of patients. In the large majority of cases (28 per cent) the service prescribed was the administration of injections. Dressings were required in 6 per cent of cases and bedside care and observation in 2 per cent or less.

Admission to some form of institution (chronic disease hospital, nursing home, convalescent home, domiciliary institution, etc.) was recommended for 34 per cent of patients. Social service was recommended for 45 per cent of cases.

It is interesting to note that recommendations in the area of rehabilitation were made for only 24 per cent of patients mostly in the form of physical therapy. Dental care seems to have been almost entirely ignored.

The recommendations listed above, extensive as they are, do not necessarily constitute a complete catalogue of patient need. Nor do they represent the most

effective use of community resources. They are deeply colored by the orientations of the prescribing physician and must be regarded accordingly.

Compliance with physician recommendations was reviewed for each item separately. Services that were received as recommended, or received in a different but equally satisfactory form, were taken to indicate full compliance. Where a service was not received, or received in partial or incomplete form, a deficiency was considered to exist. The data on lapses in service are also presented in Table 7.

More than half (51 per cent) of all patients did not comply with one or more recommendations. Deficiencies in the receipt of service arose most frequently with respect to rehabilitation services. Half the patients who had recommendation for such service did not obtain service in the manner recommended. Similarly a third of patients with recommendations with regard to personal regimen and a fifth of patients with recommendations for medical supervision and social services, respectively, did not carry out recommendations. Nursing recommendations and recommendations for institutional care were not carried out in 17 per cent and 14 per cent of cases respectively.

Due to small numbers, it is not possible to speak with confidence about which of the detailed services under the general service headings were most vulnerable to neglect. With this limitation in mind, it may be noted that, in general, clinic visits were more likely to be neglected than home visits; recommendations about diet were more subject to neglect than those about other aspects of regimen; and instructions about injections by the nurse were much less often ignored than recommendations for other forms of nursing care.

An attempt was made to classify reasons for not complying with recommendations as given by the patient or respondent at the time of the interview. Reasons for failure to follow recommendations were, in general, taken at face value and no attempt was made to explore more basic motivations (Table 8). In ten instances (12 per cent of deficiencies) the reason for the failure to comply with recommendations could be attributed to deficiencies of hospital procedure and standards of care at nursing home or similar institutions and to the lack of facilities. The patient was considered responsible for 70 per cent of deficiencies in carrying out recommendations. In general, the reasons for non-compliance related to the patient's attitude towards, or understanding of, the physician's instructions. The reasons given were classified under the following headings which are given in order of frequency:

Negligence, insufficient motivation or inability to cooperate	28%
Doubt about value of recommended procedure	14%
Resistance to recommendations	10%
Lack of family cooperation	4%
Cost	4%

The reason for non-compliance with recommendations was not known in 10 per cent of cases.

Patients who have help available to them in the home and those with more severe disability are more likely to comply with medical recommendations. Of the many variables tested only these two were significantly related to failure to act upon the physician's advice. Not related to compliance were factors such as age, sex, marital status, education, income, occupation, and living arrangements before admission. It should be noted, however, that the higher economic and educational groups were not represented in this sample of hospital ward patients. Estimates of each patients'

TABLE 8. CLASSIFICATION OF REASONS GIVEN FOR NOT COMPLYING WITH MEDICAL RECOMMENDATIONS

Reasons for lapse*	Total No. and %
All reasons	80 (100%)
Patient attitude	37 (46%)
Resistance to recommendation	8 (10%)
Insufficient motivation	10 (12%)
Does not think service of value	11 (14%)
Fear of M.D. or hospital	3 (4%)
Resistance to charity	1 (1%)
Apathy	2 (2%)
Treatment painful or distasteful	2 (2%)
Patient understanding	6 (8%)
Not aware of recommendation	4 (5%)
Did not understand treatment	2 (2%)
Patient described as negligent, senile, unintelligent, irresponsible, or alcoholic	13 (16%)
Family not cooperative	3 (4%)
Cost and financial reasons	3 (4%)
Lack of facilities	1 (1%)
Failure in referral	3 (4%)
Nursing home director uncooperative	3 (4%)
Poor standards of care at convalescent home	3 (4%)
No reasons given	8 (10%)

*Where more than one reason was given for not complying with an item of recommended service, the most prominent or relevant reason was assigned.

attitude towards the physician's recommendations were made by the hospital physician at the time of discharge and the interviewer at the time of the follow-up visit. The interviewer also commented on the patient's 'understanding' of the recommendations made by the physician based, to a large extent, on the accuracy and completeness with which the patient could describe these recommendations. There was no statistically significant relationship between attitude or understanding, as measured in this study, and the likelihood of there being lapses in complying with the physician's recommendations. This may indicate inadequacies in our assessments of attitude and understanding since this finding is at variance with the reasons actually given for lack of compliance which frequently seemed to reflect poor understanding and attitude on the part of the patient.

Services desired but not obtained

The patient and/or members of the family were asked whether there were any services which they considered necessary but did not obtain. Unmet needs for one or more services were reported by 40 per cent of patients in the sample as indicated in Table 9. These touched on many aspects of medical care including the continuity of

TABLE 9. SERVICES CONSIDERED NECESSARY BY THE PATIENT OR MEMBERS OF HIS FAMILY BUT NOT RECEIVED AND DEFICIENCIES IN SERVICES RECEIVED

Service not received or deficiency in care	No. of patients*
One or more services desired	33
A. Continuity of care	4
Care from the same physician	3
Proper arrangements for supervision after discharge	2
B. Cost and availability of care	4
Need for specified facility or service	3
Arrangements for payment	2
C. Quality and content of care	11
Deficiencies in hospital services	4
Deficiencies in outpatient clinic services	3
Deficiencies in nursing home services	1
Deficiencies in therapy	5
D. Needs for social service	19
Financial assistance	9
Information, education, and reassurance	4
Suitable employment	3
Transportation	2
Household help	2

*Since each patient may indicate more than one deficiency in each category of service, subtotals do not add up to the totals.

care and the desirability of maintaining a stable patient-physician relationship, the quality of hospital and nursing home services with special emphasis on the many shortcomings of the latter, the cost and availability of services, and the needs for social service. Unmet need for social service appeared to be the most prevalent and included requests for financial assistance, information, education or reassurance, suitable employment, transportation, and household help.

Differences among hospitals

The number of patients selected from each hospital is too small to permit comparisons among hospitals. This is made even more difficult by the fact that patients from each hospital were initially appraised and subsequently interviewed by different persons introducing a large factor of observer variation. Whatever differences are noted below must, therefore, be regarded only as clues to be pursued in future studies.

Patients from Hospital A, a large municipal hospital with university affiliations, were the poorest, least educated and most often separated from their families. Although they had the highest proportion of less disabled persons, and were not the most likely to be re-admitted to an institution, they remained there the longest once admitted. Their record of compliance with physician recommendations was the poorest.

Patients from Hospital B were intermediate in socio-economic status, most often severely disabled, most likely to be referred to community agencies, including institutions, most likely to have recommendations for care following discharge, and most likely to comply with these recommendations. Hospital B is a voluntary hospital with

university affiliations, closely identified with an ethnic segment of the population. It has instituted carefully planned discharge procedures involving physician, nurse and social worker, and maintains highly developed relationships with a variety of community agencies. It remains to be seen what contribution some of these factors make to the post-hospital course of the patient.

Hospital C is a renowned center of clinical practice and research to which patients are referred from distant places. Patients from the ward service of this hospital were the best placed economically and socially. They were the least likely to have referrals to community agencies or have services recommended following discharge. One notable exception is referral to the outpatient department which was most common for these patients.

DISCUSSION

From this study and from all the studies that we have reviewed [3-7], on the post-hospital adjustment of the discharged patient, emerge the outlines of a problem about which there is remarkable agreement. There is a substantial group of patients, characterized by the nature and severity of their illness and the paucity of their personal resources, who leave hospitals ill, disabled, and in need of much continuing care and supervision. For these patients, any one hospital admission is only an episode, sometimes a disruptive one, in a long-drawn-out process of medical and social care. For many, the post-hospital period is one of serious peril in which much of what had been gained during hospitalization can be lost and life itself endangered. Mortality rates may be as high as 10 per cent within three months [6, 7a], and 27 per cent during the first year [3]. There is continued disability and deterioration in physical capacity and function. Difficult living conditions, aggravated by family tension and disruption, are fairly common; and there is considerable anxiety about health. Persistent loss of employment, or employment in unsuitable occupations, is a major problem affecting especially the elderly, unskilled manual worker.

In spite of the great need for further medical care and supervision, large proportions of patients do not receive the care they need. In one study, 20 per cent of cases did not get medical service or received it only in part [7b], and in another study only a third of patients received satisfactory medical supervision [3]. Although social services may be needed by as many as 70 per cent of cases [4], only a relatively small proportion receive such service. This is only partly due to the absence of appropriate agencies; in many instances the available services are not fully utilized. There is, in addition, the 'personal factor' [7b]: the apparent unwillingness or inability of patients to comply with medical recommendations.

A major finding of all the studies reviewed, as of our own, is the very large amount of institutional care that patients receive. This is apparent both when the previous history of each patient is reviewed and the actual utilization during the post-discharge period is prospectively observed. Re-admissions to hospital which may occur, often more than once, in as many as a quarter of patients within one year [7c], and in about a third of patients within two years of discharge [7b], have been called "one of the great wastes in the field of medical care" [3]. FERGUSON *et al.* have estimated that in a quarter to a third of cases there are preventable factors that play an important role in bringing the patient to the hospital in the first place. They find that poor home conditions and unsuitable work are important causes of relapse and rehospitalization.

Others [7c] ascribe much less importance to environmental factors and stress the natural progression of illness as the major determinant of post-hospital experience. Although these findings relate to a selected population group, the observations of ROEMER and MYERS in Saskatchewan clearly demonstrate the importance of 'repeaters' in the larger picture of hospital utilization [8].

The successful care of chronic illness requires an unusual degree of sustained co-operation and participation on the part of patients and their families. In many instances a virtually new mode of living has to be established. This being the case, it is surprising that so little is known about patient compliance with medical recommendations and the factors that promote or hinder it.

Several of the follow-up studies reviewed above have demonstrated, as we have, the great frequency with which patients fail to abide by medical recommendations. In one study [7b], about a quarter of patients did not comply with specific medical recommendations. Lack of compliance was most frequent with recommended modifications in diet, exercise, habits, and activities. FERGUSON and MACPHAIL [6] estimate that in a third of their patients it was reasonably certain that advice was being strictly followed. In another third it was clear that the patient could not or would not cooperate. There was considerable doubt concerning the remainder.

The problem of non-compliance with medical recommendations appears to be a pervasive one. In one follow-up study of school children, discovered to have visual and hearing defects, more than 40 per cent of families in the highest economic categories failed to get the child under care as advised [9]. In another study, about 3 out of 4 families that went to clinics failed to continue under care as instructed. One or more children from half of these families secured none of the services advised. Exactly half of all recommendations made were not carried out [10].

Several studies have been reported dealing with the regularity with which recommended drugs are taken by patients. These include studies of anti-tuberculosis drugs [11-14], penicillin in acute streptococcal illness [15, 16], oral drugs in the prophylaxis of rheumatic fever [17, 18], antacids in peptic ulcer [19], and miscellaneous medications for chronically ill patients on a home care program [20, 21]. With one notable exception [14], the findings are in agreement; about half the patients do not take the drugs as prescribed.

Studies of other aspects of the medical regimen* include studies of broken clinic appointments [22], of leaving hospital against advice [23], and of failure to carry out physical therapy at home [24, 25]. As an example of the high levels of non-compliance reported may be cited the findings that "between 1942 and 1947, 52 to 72 per cent of the discharges of tuberculosis patients from all Veterans Administration Hospitals were irregular in nature" [23]. Similarly, two studies on the management of arthritis at home have shown that about a tenth of patients did not start the recommended program of physical therapy and a further third or more discontinued treatment even though symptoms persisted. The difficulty of bringing about changes in the patient's dietary habits is generally recognized [26, 27]. This is especially true of the obese for

*The literature concerning participation in various preventive programs such as poliomyelitis and influenza immunization, tuberculin testing and the use of preventive dental services is not reviewed because specific physician recommendations to individual patients are not a feature of these situations.

whom "the results of treatment . . . are remarkably similar and remarkably poor" [28].

Why do patients ignore the recommendations of their physicians? There are, of course, the obvious answers. People know little about disease in general [29], and not much about the illnesses which they themselves or members of their families have [18, 30-32]. Doctors and nurses tell the patient less than he wants or needs to know [30, 33, 34], and patients have trouble understanding the little they are told [35, 36]. The purpose of prescribed medications and their mode of action are often very imperfectly understood [20, 21, 32]. Here are some illustrative examples. Only about half of simple questions concerning 10 common diseases were correctly answered by four groups of persons from different parts of the country [29]. Of a group of persons under care at an outpatient department in a large city "one half . . . had no accurate comprehension of their condition beyond the name for it, and some did not even know the name" [31]. Very few patients with peptic ulcer, or their wives, knew that acid was secreted by the stomach. (One wife knew her husband had acid because "it turns his wrist watch black" [32]). Only 12 out of 26 persons in a home care program had a reasonably accurate idea of the purpose of the medications they received [20]. In six hospitals only about half of the inpatients from the private and ward services, and one tenth of the outpatients, remembered having received instructions from the nurse. As many as 42 per cent of all definitions given by patients for a list of words commonly used by physicians were judged to be inadequate [36]. The barriers to effective communication between physicians and nurses on the one hand and the patient on the other seem formidable. The providers of medical care need to remind themselves that a great deal of effort on behalf of the patient may be wasted unless pains are taken to assure patient understanding and cooperation.

Several studies have shown that instruction does not necessarily lead to knowledge, and knowledge does not always result in appropriate action. Parents in a dental clinic were less receptive to preventive information than to therapeutic advice; also those who already knew something about dental health understood the message more clearly [34]. Although 95 per cent of families knew in what way and for how long penicillin was to be taken in the treatment of an acute streptococcal infection, only 8 per cent of sick persons in these families actually completed the 10-day course of treatment prescribed [16]. Knowledge has not been found to be related to completion of recommended dental treatment [34], or to adherence to a peptic ulcer regimen [37]. Partial knowledge may have unforeseen consequences. In one study [20], "patients who knew what action their medications had were tempted to alter the dosage of their medicines when symptoms changed." In a rheumatic prophylaxis program [18], the crucial factor that determined the knowledge that the mother had about the illness and the regimen to be followed, and the degree of her participation in the recommended program, was the opinion that she thought the doctors at the clinic had of her as a person and a mother. It was this that determined the extent of her 'positive identification' with the program. Similarly, PRATT and her colleagues report that more important to cooperation than knowledge and understanding was that the patient agree fully with the diagnosis and plans of the physicians, ". . . for the patients who agree with the physician's diagnosis and plans were found to complete their care in every case, while a significant number of those not agreeing completely with the doctor's formulation, left the physician" [30].

It is clear from the above that many factors are involved in determining patient compliance with the recommendations of the physician. There have been some attempts to formulate a general theory of health behavior that would embrace the various facts observed and lead on to new research [38-40]; but much remains to be learnt in an area of major significance to the reorganization of health services and the provision of medical care.

From the viewpoint of medical organization, the most important lesson to be learnt from having observed how patients fare following discharge from hospital is the urgent need for mechanisms to assure the continuity of care and supervision of chronically ill patients. The need for this is amply documented in our study and the more extensive studies that we have reviewed. What remains to be considered is who is responsible for pursuing this objective; what mechanisms can be employed to assure better performance with available resources and what social returns are to be hoped for?

The problem is so large, and the varieties of care required so many, that only a general community effort, through both private and public agencies, can meet the need. Given community support, the patient's private physician must assume responsibility for long-term supervision and for obtaining and coordinating the service of the various agencies able to help his patient. There is, however, a large group of patients, such as those observed in this study, for whom care seems to revolve around the hospital, its ancillary custodial institutions, and the hospital outpatient clinic. It is suggested that for these, the hospital might assume a much more aggressive and extensive care-providing and care-coordinating role.

It is realized that not all patients leaving hospital need extensive follow-up and supervision. In any case, the limited resources of the community and of the hospital would not permit this luxury. We need to recognize, preferably early during his hospital stay, and certainly before discharge from hospital, the patient who is likely to require help. Unfortunately our ability to do this is rather limited. In our own study, it was not possible to predict patient behavior from judgments made by the physicians or social worker. Others have found no way of predicting which patients would or would not make medication 'errors,' [21] and have noted the existence of many factors that seriously jeopardize recovery is recognized only as a result of continuing supervision following discharge from hospital [6, 7a]. These limitations notwithstanding, it is possible to recognize a high risk group having the following characteristics: old age, chronic illness, repeated prior hospitalization, separation from family, poverty, and unskilled manual employment without the immediate prospect of a job upon discharge. Poor knowledge of English and defective vision or hearing may be additional handicaps. HARNETT and MAIR [7b] consider the first three months following discharge to be a critical period during which problems tend to be most severe and preventive action most effective. It may be practicable, therefore, for the hospital to plan to supervise a selected group of patients for a limited period of time following discharge during which a more complete social diagnosis may be made and the need, or lack of need, for long-term supervision firmly established. Meanwhile, with further study and research, our methods for making a 'social prognosis' [7c] may become continually more discriminating. Among these methods one might include the development and testing of social questionnaires for patient screening [41], and the joint evaluation of inpatients by physician, nurse and social worker. In any event, a plan for action must be evolved before the patient is

discharged, and the patient and his family carefully prepared for what may lie ahead. Anticipatory guidance is an often neglected tool in clinical and social medicine.

The opportunity for social as well as clinical diagnosis and treatment should be readily available while the patient is in hospital. There is opportunity for careful instruction and preparation prior to discharge of the patient and members of his family. But how is the patient to be supervised, and his care coordinated after discharge? JENSEN *et al.* have proposed the 'extramural resident': nothing less than a personal physician provided by the hospital. Indeed, the considerable success of their experiment provides much food for thought [3]*. Other patterns of care are now evolving in connection with the outpatient departments of university hospitals [42], hospital-based group practice and a variety of after-care services, including organized home care, based upon the hospital [43]. Health departments could play a leading role in stimulating further development along these lines [44]. There is room for further experimentation. It should be borne in mind, however, that the patient's family is still the major resource in caring for him and an important ally in assuring compliance with the physician's recommendation. A primary purpose of after-care should be to restore, preserve and support the family in caring for its own sick.

Since it is generally agreed that medical care is a good thing—and the more the better—it may be thought foolish to raise the question of return on the social investment in the care of the chronically ill discharged patient. Fortunately the experience reported has been encouraging [3, 6, 7]. JENSEN *et al.* in particular have shown how successful the extramural resident was in making diagnosis after discharge in cases that had baffled the hospital staff; providing direct care for the patient at home; mobilizing agencies on behalf of the patient; bringing about patient compliance with the physician's recommendations; and in preventing hospitalization, or shortening hospital stay when this became necessary.

But what of the patient himself? Are the chances of his recovery or social productivity improved through the provision of after-care? In our own study we were unable to establish a relationship between compliance with medical recommendations and mortality, changes in disability or the volume of institutional care required. CURRAN and FERGUSON [7b] attempted to provide for the patients under observation whatever services were available within the community. The results were generally disappointing. These findings require confirmation. In the meantime they may be used to emphasize the need for early intervention before physical and social pathology have become irreversible.

SUMMARY

A study was made of 82 patients with selected illnesses of specified severity before and after discharge from the ward services of three general hospitals in a metropolitan community. An initial appraisal was made by a resident physician who evaluated the health status of each patient and made recommendations for care and supervision following discharge from hospital. After an average period of 3 months, each patient was visited by a student of social work who reconstructed the course of events following discharge and determined the extent to which the physicians' recommendations

*Exactly 20 years later, the seeds sown in Syracuse by JENSEN *et al.* seem to have sprouted. The Department of Social Welfare has begun to use a new general practice residency at St. Joseph's Hospital to provide continuous care to 500 welfare clients (*Med. Tribune* 4, 3, 12 August 1963).

were complied with and the reasons for non-compliance. The usual consequences of chronic illness—persistent disability, unemployment and recurrent and lengthy institutionalization—were amply evident in this group. So was the fact that the burden of continued care falls heavily upon the members of the family. Other sources of help were trivial by comparison. The recommendations made by the discharging physician constitute an interesting, and sobering, inventory of continued need for care. More than a half of all patients did not comply with one or more recommendations made by the physician. In addition, about 40 per cent of patients reported unmet need for one or more services touching upon many aspects of medical care. A variety of lessons relevant to the organized provision of care may be drawn from a consideration of the services needed and desired by patients and of the reasons for, and factors related to, non-compliance with medical recommendations.

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