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AMBULANT REHABILITATION OF PATIENTS WITH CHRONIC RHEUMATIC DISEASE

A Fourteen-month Clinical Trial. A preliminary report

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ABSTRACT. Experiences of the rehabilitation of patients with chronic rheumatic disease are presented. A system is worked out to register the remedies applied by physician, physiotherapist, occupational therapist and social worker, as well as a detailed list of usual goals, medical, functional and social. 285 patients have been followed for 3–14 months. The results are graded according to defined principles, and have as far as possible been estimated by objective measurements. The best results have been obtained in functional classes II–III. We have not wished to use an untreated group of patients as control. The detailed analysis has been made using a computer. For the future, development of methods to quantitate functions in daily life, to control and guide functional training and surgical treatment seem important.

Experience has shown that a conventional outpatient department is unable to cope with the therapeutic and social requirements of patients with chronic disabling rheumatic disease. Modern trends especially in the hospital treatment of such patients, medically and surgically, have increased the need for an ambulatorium with resources for rehabilitation and follow-up of the patients (1, 2, 3). Such an ambulatorium would be able to reduce the number of hospital days per patient and at the same time offer more qualified treatment to those patients who, owing to certain regulations of the National Health Insurance Board (Riksförsäkringsverket), cannot be admitted to its hospitals and departments for such treatment and rehabilitation (the beds of the Department of Rheumatology, Lund, are at the disposal of the National Health Insurance Board).

The tasks of such an ambulatorium should be as follows.

1. To trace and treat early cases of rheumatoid arthritis and other chronic arthritic diseases. Early information and training of the patients will help them to adapt themselves to their situation. An important part of such a programme is instructions in the prevention of contractures, in suitable physicial exercises, and ways to protect the joints in daily life. Equally important is the use, when possible, of technical aids to protect the joints.

2. To offer a continuous rehabilitation and medical control of already disabled patients. This is very important for those patients who are receiving a disability pension or an old-age pension and are therefore not entitled to admission to the inpatient department for medical and surgical treatment and rehabilitation.

3. To assess (at the request of National Social Insurance Board) the working capacity of patients applying for a disability pension.

4. To evaluate indications for surgical treatment, including evaluation of the patient's ability to cooperate in postoperative training in order to obtain a good functional result. With our still limited resources for surgery such an investigation should always be made before an operation is offered to the patient.

5. When working with illnesses of this type with complicated medical, functional and social problems, it is important to determine the goals in these respects for every single patient (e.g., reduction of activity of disease, enable the patient to eat or dress by herself, vocational adaptation to the limitations set by the disease). One of the tasks of the ambulatorium has been to establish a systematic definition of means and goals for treatment, and, at regular controls, to evaluate the degree to which the goals were reached (see below).

6. To provide training courses for different categories of personnel.

So far, we have no such ambulatorium for all-round rehabilitation of patients with rheumatic diseases in Scandinavia. It was therefore considered desirable to start a clinical trial in order to find out: (*a*) The types and numbers of patients that compose the clientele of this service. (*b*) Therapeutic and social requirements of the clientele. (*c*) Resources necessary to cope with these requirements: equipment, personnel, organisation.

The trial was started in April 1968 and continued until December 1969. For practical, tecnical and analytical reasons the results were evaluated only up to the end of June 1969.

Personnel

One physician, 1 occupational therapist, 1 physiotherapist, 1 secretary, 1 social worker (30 hours a week), 1 assistant nurse (30 hours a week). An orthopedic surgeon and a hand surgeon each attended the service for 1 hour a week.

Recording of Data

It was considered desirable to collect a fairly comprehensive amount of data to facilitate estimation of work, costs and effectiveness of such an ambulatorium as well as to facilitate recognition of effects of organisational changes, if any, made during the trial. Coded records of the following details were made in the patients' record sheets: (i) Characteristics of the patients: medical, functional and social. (ii) Treatment given and other measures undertaken by different members of the team. (iii) The aims of treatment: medical, functional and social. (iv) Results of treatment: the extent to which the goal set was achieved.

In a special study the time that different members of the team spent with the patient was recorded.

A computer analysis was made of certain data concerning the structure of the material, the results of certain therapeutic measures and the extent to which the goals were achieved.

Organisation of Work

As soon as a patient was referred to us he was furnished with a questionaire concerning the history of his illness, previous hospitalizations, present joint symptoms, capacity in activities of daily living (ADL) and in occupation, and social conditions.

The patient was requested to fill in the questionnaire and return it to us. On the day the patient was to attend the ambulatorium the questionnaire was dealt with at the morning conference of the team, when the work for the day was planned. On the basis of the answer in questionnaires filled in by "first visits" and of knowledge about patients returning for control it is possible to set up a time-table for the patient. From April 1968 to January 1969 a circulation record was set up for each visit of a patient in which the assistant nurse recorded the waiting times, the time used for the examination and treatment by different members of the team and for conferences about this patient (see below).

The physician, the occupational therapist, social worker and physiotherapist made notes of their measures on special forms. At the end of the day's work all members of the team met and discussed and listed the goals for the treatment of the new patients seen that day, and the results obtained for the patients seen previously.

Most patients require examination also at other departments and laboratory investigations before it is possible to decide upon the goal of treatment.

The visits may be divided into the following categories.

(*a*) First visits when the patients were, as a rule, seen by all the members of the team.

(*b*) Re-visits for supplementary examination and to check that the patient had complied with instructions given by the physiotherapist or occupational therapist and for intra-articular steroid injections, medical instructions, etc.

(*c*) 3-, 6-, and 12-month follow-up examinations with evaluation of the results of treatment, if possible by objective measures.

(*d*) Day-treatment, i.e. the patients spend the day at the Department but sleep at home or at the hospital "hotel" at Lund.

Evaluation of the home situation was performed in 50 cases by home visits. Such visits are necessary for patients who need technical appliances in the home. Further, it is often necessary to plan certain alterations in the house or flat, especially in the kitchen and bath- and bed-room. The patients were visited by one or more members of the team, who were well acquainted with her functional and medical problems, usually the occupa-

Table I. *Diagnoses (308 patients)*

	♂	♀	Total
Definite and probable RA	58	185	243
Juvenile RA	0	7	7
Anchylosing spondylitis	4	1	5
Gout	3	0	3
Psoriatic arthropathies	2	0	2
Postinfectious arthritis	7	7	14
Arthrosis def. cox + gen.	3	13	16
Arthraligia, Heberden, etc.	5	13	18
	82	226	308

Table III. *Classification according to function*

Class	
I	Can manage activities of daily living without difficulty
II	Can usually manage activities of daily living despite pain, stiffness, reduced mobility of joints
III	Partially dependent on help from other person in daily life and home management
IV	Completely disabled, bound to wheel-chair or bedridden. Totally dependent on help from other person

tional therapist and physiotherapist, but often also the social worker. Careful registration of the measures and goals set concerning home situation will with time give a more complete picture of the environmental problems of patients with chronic rheumatic diseases.

Information and Home Programme

The team and Professor Ulrich Moritz at the Department of Physiotherapy have together worked out programmes for training of hands, shoulders, knees, hips, etc. Instructions supplemented by a series of instructive photographs (4) for protection of the joints have been worked out in association with the occupational therapist. A collection of sheets with information on the effects and side-effects of various drugs and information sheets explaining the most important operations and their pre- and post-operative treatment has been worked out.

The patients are thus given all the necessary information and training to be able to take part in the responsibility for the treatment of their disease.

Composition of Clientele

Between April 1968 and June 1969 this outpatient service had 308 first visits, 1 123 re-visits and control visits, and 50 visits at the patients' homes. Data concerning 308 patients were analysed. Of these patients, 285 had chron c polyarthritis, most of them rheumatoid arthritis. Only patients with polyarthritis and a few with severe coxarthrosis are accounted for here (285 patients). Tables I–II summarize the material distributed according to diagnosis, age, duration of disease and functional class according to American Rheumatism Associations' criteria (slightly modified, see Table III).

As expected, there were three times as many women as men. Most of the patients were between 50 and 69 years of age.

The distribution of the patients according to functional ability is of particular interest (Table II). A little more than a third of the patients were only slightly disabled (functional classes I and II constituted 38 %). Almost half of the patients (45 %) belonged to functional class III, where the patients have difficulties with activities in daily life, ambulation, and have reduced physical capacity at home and at work. A minor percentage (17 %) were practically completely disabled and could not manage daily life by themselves (functional class IV).

Table 4 shows the occurrence of reduced ability in different activities of daily living. Many (90 %)

Table II. *Distribution of sex, age and duration of disease within the functional classes (285 patients with chronic polyarthritis)*

Functional class	Number of patients ♂	♀	Total	% of total	Age years mean (variation)	Duration of disease years mean (variation)
I	5	18	23	8	49 (3–76)	11 (1–35)
II	27	58	85	30	53 (18–79)	13 (1–42)
III	31	97	128	45	58 (17–83)	18 (1–47)
IV	12	37	49	17	59 (27–75)	18 (1–39)

Table IV. *Effect of disease on certain ADL functions*

Effect	No. of patients	% of total
Walking impaired	256	90
Needs crutches or elbow-crutches	64	22
Needs wheel-chair, occasionally	29	10
Needs wheel-chair, permanently	17	6
Difficulties in:		
getting into and out of bath	202	71
leaving the flat without aid	102	36
walking up and downstairs	240	84
managing daily hygiene	157	55
dressing	178	62
use of knife, fork and spoon	127	45
managing housework	189	66

found it difficult to walk mainly because of involvement of the feet and toes; 22% required crutches or sticks because of advanced involvement of hips and knees; 16% were partly or entirely wheelchair-bound; 55% had difficulties with their daily hygiene; 62% with dressing and undressing and 42% with eating (impaired hand–elbow function).

Some 52% had a disability pension or disability allowance and 18% an old-age pension. Of the remaining 30%, as many as 19% had a temporary daily sickness allowance at their first visit to the department, 11% were still actively working. 13% were receiving municipal housing supplement, 6% a disability supplement. It was found, however, that approximately 15% of the patients, though severely handicapped, were not receiving the financial support to which they were entitled.

As many as 59% of the patients were living in modern homes. Only 2% had homes specially designed for invalids.

Production

The production of the unit may be characterized in different ways. One such way is the production of statistics on various measures undertaken. The average number of measures per patient in different functional classes is given in Table V. No detailed list or statistics on individual measures are given in this report. Examples of common measures of different members of the group are the following:

Physician

Different types of medical treatment, intra-articular injections of steroids and osmic acid. Consultations at other departments, especially those of orthopedic surgery, radiology, ophthalmology and internal medicine. Issue of certificates for insurance companies, disability allowance. Housing problems, etc.

Physiotherapist

Evaluation of functional capacity. Instructions to the patient and/or relatives in physical training of the shoulders, elbows, hands, hips, knees, and ankles. Referral to local physiotherapists for treatment. Individual selection of proper walking devices and wheel chairs. Training to improve ambulation. Home visits.

Occupational therapist

Evaluation of functional capacity. Training to improve activities of daily living. Training to improve ability to work in kitchen and selection of proper self-help devices. Instruction in methods for protection of joints in daily life. Replanning of home management.

Table V. *Average number of measures to which individual patients of different functional classes were subjected by various members of the team*

Member	Number of measures per patient			
	Functional class I	Functional class II	Functional class III	Functional class IV
Physician	2.3	4.9	4.9	5.3
Physiotherapist	1.3	3.9	4.6	4.7
Occupational therapist	1.3	4.7	6.0	6.5
Social worker	0.7	2.2	2.7	3.0
All members	5.6	15.7	18.2	19.5

Social worker

Investigation and checking the patient's need and right to financial support. Inspection of patients' homes and financial arrangements.[1] Advice in education. Contacts with the vocational agency.

The main task of the physician was to coordinate the activities of the team and together with the team to set up realistic objectives for the patients and give adequate medical treatment as well as local injections of steroids. Although the number had to be restricted because of limited time, as many as 176 patients were referred for orthopedic and hand surgery consultations. The most usual orthopedic problems discussed are early and late arthritic changes and deformities in hips and knees, and their influence on walking and transferring. Usual hand problems are painful wrists, carpal tunnel syndromes, and early as well as late changes in finger joints. Approximately 35 patients were referred to operations at the Department of Rheumatology.

These consultations took place at the Ambulatorium, which was visited once a week by the orthopedic surgeon and the hand surgeon or at the outpatient service of the Orthopedic Department. A considerable amount of patients required orthopedic appliances such as specially designed shoes, wrist supports, and different sorts of braces. As many as 116 patients were referred for roentgen examinations usually as part of the orthopedic evaluation and about 70 patients on one or more occasions to ophthalmological examination, mainly for control during cloroquine therapy.

The work of the physiotherapist was recorded with respect to part of the body treated. A distinction was also made between those who were mainly instructed in self-training and those referred for treatment by another physiotherapist. It was thought desirable to find out which of these procedures, i.e. "self-training" or "treatment" was more efficient.

[1] In Sweden up to 15 000 Sw.cr. (equivalent to U.S. $3 000) can be obtained for adaptation of the house or flat to the handicapped patient.

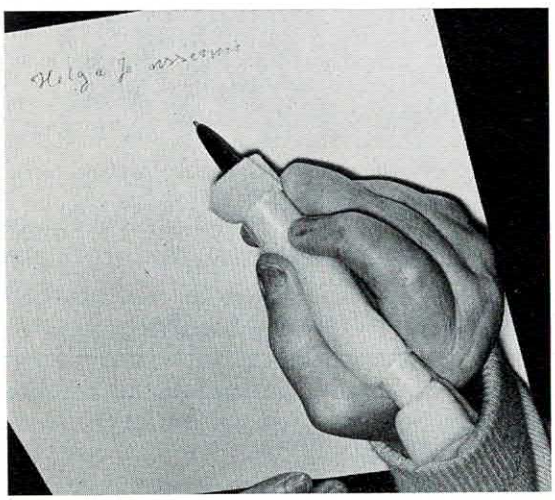

Fig. 1. Teaching the patients to thicken all handles in order to reduce the power needed for fixation is part of the education in joint protection.

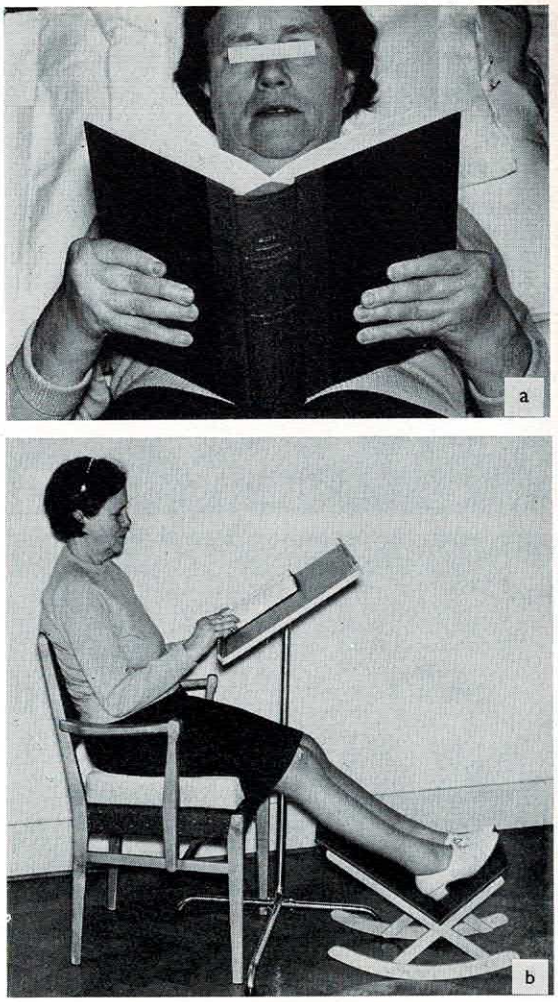

Fig. 2. (*a*) Reading in bed will load the damaged finger-joints in ulnar direction and should be avoided. (*b*) Correct sitting position for reading.

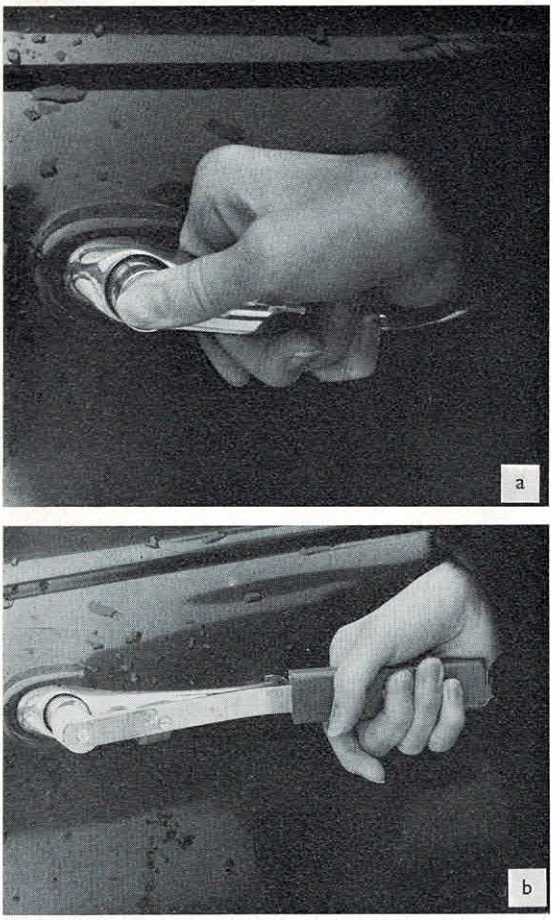

Fig. 3. (*a*) Pressing the button is dangerous to thumb p.i.p. joint. (*b*) Car door opener is used to spare the thumb p.i.p. from hyperextension (Model Gunnar Persson, Lund, Sweden).

The work of the occupational therapist was dominated by examination of ADL-function, training of ADL-activities, selection and teaching the use of technical devices and education of the patients in a joint protecting way of life and work. Methods for objectively estimating the results of her work have so far been limited but functional tests are being worked out. We have tried to find out to what extent the technical aids prescribed were actually used (Table VI).

The best documentation of the production and its output of a department is perhaps the frequency of different goals set and the degree to which they were achieved.

Examples of Different Goals (Table VII)

To teach the patients to adopt suitable sitting and resting positions and when necessary to provide them with proper chairs (Fig. 2).

To strengthen the legs (hip and knee extensors).

To improve the mobility of the hips, joints, and and ankles.

To teach the patients how to protect their joints, especially the hands, in their daily life (Fig. 1).

To teach the patients how to manage activities of daily living with technical devices, to manage transfer into and out of the bath, wheel chair, and coping with stairs.

To improve hand function with the aid of technical devices (Fig. 3).

To see that the patient can manage to feed herself, to turn a key, to switch on the TV and to open the car door by providing her with necessary devices.

To make the patient as comfortable as possible in a specially adjusted wheel-chair.

Improvement in ambulation indoors and outdoors and in–out.

Upgrade the patient to a better functional class.

Social goals concerning education, change of occupation and economy (disability pension).

Improvement of housing or change of apartment.

Time Tables

A further characteristic of the activity is ultimately the time which the individual members of the

Table VI. *Example of results of measures (occupational therapist); degree of use of aids tried out*

Type of aid	No. of patients controlled	Results, % Good (1)	Doubtful (2)	Not evaluable (4)	None (5)
Technical aid for bathroom–toilet	94	68	2	17	13
Technical aid for housework	106	84	—	9	7
Working chairs	73	85	3	8	4

Table VII. *Achievement of goals at last control (after 3,6 and 12 months); functional classes I, II, III, IV*

Goal	Number of patients controlled	Controlled patients who achieved goals, % Good (1)	Doubtful (2)	Not evaluable (4)	Worse (5)
Medical					
Reduce activity of disease	53	45[a]	19	11	25
Relieve depression and increase motivation	62	26	32	8	34
Eliminate other disease or symptoms	69	28	16	28	28
Functional					
Retain present mobility of weight-bearing joints by instruction in prophylactic treatment of contractures, correct sitting and resting positions	126	50	17	10	23
Increase mobility of shoulders and elbows	100	30	20	13	37
Increase mobility of hips, knees and ankles	57	30	19	14	37
Increase strength of knee and hip extensors	141	40	11	17	32
Manage dressing with technical aids	60	37	17	10	36
Manage hygiene with technical aids	53	30	19	19	32
Take a bath or shower with technical aids	62	50	8	18	24
Manage simple cooking, stove, taps, pots, cutting, etc.	47	45	15	19	21
Upgrade patients in functional class (e. g. III→II)	41	15	4	66	15
Social					
Improve home environments	76	18	4	69	9

[a] Determined mainly by reduction of ESR > 20 mm/1 hr.

team need for examining, treating and instructing each type of patient seen at the Department. Data on these points are given in Table VIII. On an average about one hour is spent with the doctor, 3/4 hour with physiotherapist and occupational therapist when the patient first visits the ambulatorium. It should be observed that the figures refer *only to the time the patient is in direct contact* with a member of the team. Thus it *does not* include dictation of the case records, writing of certificates, telephoning or other clerical work. Neither does it include the time spent by the members of the team at conferences which required, on an average, 10–15 minutes per patient and visit.

The long time devoted to the patients is due to the relatively advanced disability and complicated therapeutic problems in most of them. This is demonstrated by the fact that the number of therapeutic measures per patient was larger in the two most disabled functional classes than in the less disabled class (Table V).

Besides, these patients often hide their problems behind a smiling mask. The establishment of good personal contact between staff and patients is time-consuming but necessary in order to get the full cooperation of the patient.

As a rule, the patients were seen and treated by two or three members of the team at one visit and each visit often lasted several hours. When treatment included thorough instructions in diferwerent self training programmes the patients attended the Ambulatorium daily for a week or more.

Control of Output

Statistics on measures and goals describe the means and orientation of the activity. Whether the

Table VIII. *Time the patients and the various members of the team spent together*

M, mean; (var), variation

Member	First visit *M* (var)	Re-visit *M* (var)	Home visit *M* (var)
Physician	61 (10–120)	23 (5– 90)	
Occupational therapist	38 (10– 80)	30 (5–115)	91 (30–195)
Social worker	33 (10– 70)	21 (5– 85)	
Physiotherapist	45 (15–100)	37 (5– 95)	92 (30–195)

Table IX. *Achievement of goals in different functional classes. Example 1. Increase of mobility of lower limbs (hips–knees)*

Functional class	No. of patients	Distribution of results: Good (1)	Doubtful (2)	Not evaluable (4)	Worse (5)
II	8	50	50	0	0
III	32	34	28	16	22
IV	16	12	62	13	13

activity is of any true value, i.e. whether it is really worthwhile, can be shown only by an analysis of the results. The trial therefore included objective evaluation of the results approximately 3, 6, and 12 months after the goals of treatment had been decided upon. The results are codified in the following way:

1. Goal achieved. Verified by objective measurement of muscle strength, range of movement of joints, etc. Result of practical value to the patient.
2. Goal only partly achieved; doubtful whether the result is of any value to the patient.
3. No effect (includes also uncertain effect).
4. Not evaluable, i.e. treatment not concluded, or treatment planned not yet started.
5. Worse. Confirmed by objective measurements.

Of the 285 patients, 60 were controlled after 3 months, 94 after 3 and 6 months, and 84 after 3, 6, and 9–12 months.

Table VII shows some of the results of the activity. This report is limited to goals set for at least 35 patients. The analysis includes patients from all four functional classes, thus both relatively mild cases with good motivation and advanced cases where the patients are often resigned.

Good improvement (code 1) was achieved in 30 to 50 % of the patients. One example is, for instance, when a patient with painful stretching of the knee can, after training of the knee extensors, walk up and down steps without pain. Another example is when a patient can recover ability to comb her hair after treatment has reduced the pain and increased the range of motion of the shoulder and/or elbow. In about 45 % of the patients where the goal was to manage simple cooking and household work this was achieved by combined self-training and the use of technical aids and machines. Difficulties in taking a bath or shower were overcome in 50 % of the cases by training and suitable devices. The operations planned and carried out during the trial do not yet influence the results.

It is of interest to correlate the results of treatment to the patient's original functional condition (Tables IX, X, XI and XII. The treatment was most successful when the patients were less disabled and the duration of disease was relatively short.

Table X. *Achievement of goals in different functional classes. Example 2. Increase of strength of lower limbs (knee extensors)*

Functional class	No. of patients	Distribution of resluts, %: Good (1)	Doubtful (2)	Not evaluable (4)	Worse (5)
II	46	45	24	9	22
III	74	35	38	22	5
IV	15	36	32	26	6

Table XI. *Achievement of goals in different functional classes. Example 3. Manage daily hygiene + toilet visits (excl. bath) with technical aids*

Functional class	No. of patients	Distribution of results, %: Good (1)	Doubtful (2)	Not evaluable (4)	Worse (5)
II	6	66	17	17	
III	30	34	40	13	13
IV	17	12	53	29	6

Table XII. *Achievement of goals in different functional classes. Example 4. Manage dressing with technical aids*

Functional class	No. of patients	Distribution of results. % Good (1)	Doubtful (2)	Not evaluable (4)	Worse (5)
II	3	67	33	0	0
III	34	50	35	3	12
IV	23	13	48	22	17

In most cases the patients reach a stage where they begin to accept their handicap and can be induced to take part in a prophylactic training programme and learn to protect their joints in daily life. This seems to be the most favourable time to start rehabilitation of the patients. The results were best in functional classes II and III. Intensity of the disease and resignation after many years disease, often combined with chronic reactive mental depression constitute an unfavourable therapeutic situation.

Yet there are considerable opportunities to also help patients in functional class IV, e.g. giving them a specially adjusted wheel-chair, teaching them to use lifts for transferring in–out of bed and bath, and by changing their home environments. Only temporary improvements were achieved in muscle strength, range of motion and activities in work and housing. We often noticed how a class IV patient, well adapted to her handicap, became restless and anxious during a time of intensified treatment at the Ambulatorium. But it is probable that some of these patients could be more successfully treated as inpatients in a rehabilitation hospital.

Developmental Trends

Orthopedic surgery

According to our experience, surgery can contribute valuably to the rehabilitation of these patients. By intimate cooperation with the orthopedic surgeon and the hand surgeon at the Ambulatorium it is possible to formulate a thorough evaluation of the patient before operation is decided upon. The detailed knowledge the team has of the patient and the measurable results of instructions and self-training provide a good guide in the selected surgical resources.

Day-care

The need of facilities for day care will increase. Since February 1969, 1–2 beds at the hospital hotel have been reserved for the day-care of patients with rheumatic diseases, especially for those undergoing orthopedic investigation and treatment. A rehabilitation programme comprising 3–4–5 hours' active cooperation a day with the physiotherapist and the occupational therapist, together with rest and social life in the hotel produced very encouraging results.

Functional tests

Experience gained in the evaluation of the results achieved has clearly shown the need for more and better methods for measuring physical performance. Endeavours to devise such methods are in progress. An accurate estimation of the result is a requisite for eliminating inadequate methods of treatment and may initiate the development of more efficient therapeutic procedures. At present we are trying to develop suitable methods for testing the performance of the lower limbs. A set of hand function tests has been worked out (Junerfält, unpublished).

SUMMARY

A report is presented of experience gained in a 14 month clinical trial of ambulant rehabilitation of patients with chronic rheumatoid disease. The aims of such an investigation are defined.

For documentation of such a trial a special system of registration has been evolved for data characterising the patient material, the various forms of treatment prescribed by physician and surgeon, occupational therapist, physiotherapist and social worker and the therapeutic goals of the combined unit.

The organisation of such a trial is described. An important feature is the conference with the various members of the team, held at the beginning and the end of the day. At these meetings a detailed programme of treatment is outlined to the patients' individual needs.

Home visits have proved most beneficial in organising a suitable individual programme for treatment. Day care is gradually and increasingly assuming a more important role.

Importance has been stressed in instructing and

informing the patient. Emphasis has been laid on thorough individual information regarding locomotor independence at home or assistance by relatives, giving the patient a feeling of responsibility.

Different standardised, written gymnastic programmes have been formulated as well as written instructions on joint protection, the effects and side effects of various commonly used medicines and the surgical aims and pre- and post-operative management.

The results of the measures taken and the evaluation of the extent to which the objectives of treatment were achieved in 285 patients with chronic polyarthritis, mainly rheumatoid arthritis, are assessed and recorded. As far as possible these evaluations were based on objective findings. The results were assessed 3, 6, and 12 months after the beginning of the trial.

Many of the therapeutic measures and aims resulted in an improvement for the patient medically, socially, and functionally. A positive result was often attained in those cases where the invalidity was not pronounced (functional class II or III).

An important task for the future is the development of increased and improved methods to measure physical function—that is to say, means for guiding and controlling the results of functional training.

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