Investigation of the social status of paraplegic individuals after medical rehabilitation

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The social services of the German centres for spinal cord injuries compiled social data on 2000 recently injured paraplegics. The aim of the study was to determine whether and to what extent patients had been reintegrated to jobs after completion of physical rehabilitation treatment. A 31-point questionnaire surveyed all relevant data pertaining to the projected professional vita. The results for the medically rehabilitated population ($n=651$) indicate that 45% returned to their previous job, school or college. Intensified use of computers and advanced academic backgrounds of afflicted individuals contribute to a higher chance for reintegration at a previous job. Our social statistics also include data on living conditions and social support. Household caretaking support is offered by family members in 73% of cases, while 5% permanently live in nursing homes.

Keywords: spinal cord injury; paraplegia; rehabilitation; vocational reintegration; living conditions; social support

Introduction

The Federal Republic of Germany has a total of 22 spinal cord injuries centres (as of 1/1/96) for those with paraplegia. These institutions are for the rehabilitation of persons with spinal cord injuries (SCIC) preparing them for vocational and social reintegration. The locations of the present facilities in Germany are indicated in Figure 1. The psycho-social consequences of spinal paralysis are dependent on the severity of the lesion, the patient's profession, family status, age, and the social environment at the onset of disability. The complexity of the problems associated with the impairment requires specially qualified assistance, which can only be supplied by specially equipped clinics. The diagnostic and therapeutic measures are supplemented in all of the centres by specialized social support services which provide counselling and long-term assistance for patients on aspects of reintegration. The social support services base their efforts on modern concepts of case-work. Interdisciplinary teams cooperate in an integrated environment with other involved health and social services. The German vocational rehabilitation centres for the disabled at present provide a capacity for approximately 20,000 adults (Berufsförderungswerk: secondary vocational training) and 12,000 adolescents (Berufsbildungswerk: primary vocational training). These institutions were created by a concerted effort by the state and by federal governments in the late 60s and early 70s. At

present there are 48 such institutions devoted to vocational rehabilitation of the physically disabled, sensorially disabled, and developmentally impaired. Vocational rehabilitation centres for adult paraplegic patients have been concentrated in: the Berufsförderungswerk Bad Wildbad (Black Forest) and the Orthopedic Clinic of the University of Heidelberg (Kurt-Lindemann-Haus).

In the early 1980s a substantially lower demand for vocational rehabilitation of paraplegic individuals was registered at these facilities. No plausible explanation for this decline has been discovered by available investigations and statistics compiled by the clinics of the employer's liability insurance association (Berufsgenossenschaften). Though there existed no vacancies in the SCIC fewer patients were admitted for vocational rehabilitation in the corresponding centres. A survey conducted by the Berufsförderungswerk Bad Wildbad in 1987 involving data from all SCICs resulted in the impression that more beds for paraplegic patients in special centres are required. Many required urgent medical rehabilitation measures which could not be offered because of the limited capacity in these special treatment centres. All centres reported that they were operating at full capacity. Thus the impression was that there was a lack of vocational rehabilitation facilities, while, in fact, the demand for these programs was decreasing. This was quite surprising. There was no explanation from the available literature. Investigations on professional and career developments of hospital-discharged paraplegic

Figure 1 Location of the present German facilities for SCI rehabilitation

patients did not exist. The Berufsförderungswerk Bad Wildbad thus initiated a survey to elucidate the conditions of hospital-discharged paraplegic patients, as this was the responsibility of the social support services.

An initial preinvestigation was conducted as a random sampling through interviews in some of the SCICs medical centres. This was supposed to provide information on:

- the age structure of recently injured individuals
- the ratio of paraplegic *vs* tetraplegic patients
- the cause of impairment
- the requirement for additional counselling, in special reference to mobility, vocational development, living conditions, caretaking services, etc.
- social data previously acquired by medical centres
- the demand for a uniform data acquisition network by the social services
- the demand for admissions to the vocational development centres

The main question on whether the decreasing demand for admissions to the vocational development centres was related to a change in the socio-demographic structure among paraplegic individuals could not be answered. However, new questions arose from this preinvestigation:

1. Did more patients previously work in commercial services and business-related careers?
2. Do more employers accept disabled employees, and to which extent do they reemploy them?
3. Do improved technical developments permit the individual to return to the job?

4. Are patients on the average older and thus more reluctant to consider training in a new career?

5. Did the number of patients with severe lesions increase?

6. Are more paraplegic individuals living in nursing homes than before?

7. Are afflicted individuals not sufficiently aware of their options for vocational rehabilitation?

In order to answer these questions it seemed necessary for a prolonged investigation by collecting pertinent data from the SCICs.

The results of the initial preinvestigation were presented at the Meeting of the Social Services at the SCICs in December of 1988 held at the clinic 'Hohe Warte' in Bayreuth, Germany.

The attending members of the SCICs agreed on the proposal to compile general statistics and expressed their willingness to participate in the effort.

A two part questionnaire was devised. The first section included all relevant personal data, ie last name, first name, date of birth, and address. This section was intended to be separated from the form before mailing the data sheets to the evaluators at Heidelberg for data processing. The personal data section was to remain in the medical records of the patients at the SCICs. The second section, being the actual questionnaire, comprised 31 questions on the social status of the paraplegic individuals.

The survey was to be completed for each paraplegic patient. The effective date was supposed to be the day of hospital discharge. It was advised to have social workers fill in the forms together with the patient.

The forms were evaluated using a specially designed computer program, allowing individual and cross-reference evaluation. For instance: How many tetraplegic patients in the age group of less than 27 years, with care-taking provided by relatives, were reemployed by a previous employer after the disabling incident? – or: What kind of educational/professional background do patients have who were disabled by a motorbike accident and who had been admitted to a nursing home directly after hospital discharge, and which job alternatives did these individuals have? The program allows all data to be used in any direction of interest. The main point, however, is to determine the variables for vocational rehabilitation.

Materials

The first questionnaires were received in Heidelberg in 1989. Due to various complications it was not possible to run the survey over the projected time period of 5 to 10 years. It had to be terminated in 1992 with a total of 2000 forms being received.

To our knowledge, extensive data collections of this kind had not previously existed, the workgroup decided to pursue an evaluation of the results. This was delegated to a small group of project members. (Figures 2 and 3).

Among the total population almost two thirds of

the traumatic lesions were due to recreational accidents; of these 78% were males. Among individuals experiencing occupational accidents (25%) the fraction of males is even higher at 88%. (Figure 4).

Vocational rehabilitation

The initial reason for conducting this investigation was to determine the status and needs for vocational

rehabilitation among paraplegic individuals. With fewer patients demanding vocational rehabilitation than in earlier years – despite the continuously large number of patients treated in SCICs – our interest was aimed at those individuals who did not use the services offered by the vocational rehabilitation centres. The social statistic was done in a group termed ‘rehabilitation-population’ consisting of 651 patients who were considered to be suitable for vocational rehabilitation and for whom such programs seemed appropriate; of these 80% were male, 20% female. Forty-five percent of this rehabilitation-population returned to their previous job or continued school or studies after treatment. Thus 55% should be potential candidates for vocational rehabilitation measures. Twenty-five percent only had definite plans for professional development at the time of hospital discharge. The remaining 30% seemed undetermined or did not intend to take up a profession.

In order to make correlations the rehabilitation-population was divided into three groups. The first group comprised those going back to their previous job or continuing their schooling or studies after hospital discharge. The second group consisted of those intending to participate in vocational rehabilitation programs, and the third group were those who made no statements on projected professional developments.

Marked differences were noticed in terms of the educational background and professional status of individuals between the three groups. Patients who worked in previous professions – in some cases filling a different position – had a higher educational level than those who were undetermined about their future professional development. Among those taking up previous professions, 35% were trained in grade secondary schools (up to grade 9) and 24% graduates from 2-year colleges. But 60% from lower grade secondary schools and 13% graduates from 2-year colleges are among professionally undetermined individuals. Among individuals in group II intending to participate in vocational rehabilitation programs

Figure 2 Age upon admission $n=2000$

Figure 3 Distribution of Para- and Tetraplegics $n=2000$

Cause of Disability

Figure 4 Cause of Disability $n=2000$

57% had completed lower grade secondary school, 26% were secondary school graduates, and merely 7% had been 2-year college graduates.

A comparison of professional status also reveals a similar distribution. Twenty-nine percent of salaried employees (white-collar) and 24% of workers (blue-collar) were among those returning to a previous work-site, while 48% of workers and 14% of salaried employees were undetermined about their future professional development. Several peculiarities were observed in group II, ie those individuals aiming at improving their job perspectives by training/retraining in a vocational rehabilitation centre; 29% had previously started an apprenticeship, 49% were workers, and only 6% were salaried employees.

Patients having started an apprenticeship were significantly common in this group, while such individuals were notably rare in group I and III, at 6% each.

An analysis of the family status of the rehabilitation-population also yielded interesting results. The fraction of unmarried patients in group I and III were 58% and 61%, respectively, while in group II as many as 86% were unmarried.

The evaluation clearly shows that married patients rarely participate in vocational rehabilitation programs. Fifty eight percent of individuals who worked for previous employers were unmarried, 32% married.

Thus, the majority of paraplegic individuals using vocational rehabilitation measure are unmarried, either have completed a lower grade secondary school or secondary school education, and prior to disability served an apprenticeship or were employed as blue-collar workers.

Discussion

One of the initial intentions of the survey was to determine the professions of afflicted individuals. Are more patients working in the commercial services and business domain? As these individuals do not require any form of vocational rehabilitation, would this account for the decreasing demand of paralyzed people for training in the vocational rehabilitation centres?

Our data reveals that 36% of the patients who worked for former employers after hospitalization were trained in the commercial services and business sector. The use of modern electronic equipment throughout the work environment facilitates adaptations of paralyzed individuals to a previous or related job, mainly without vocational rehabilitation.

The present statistics do not reveal whether more handicapped individuals are being reemployed than in previous years. An answer to this question could only be given by a long-term statistical survey. As more workplaces are being equipped with data processing units which facilitate work for the disabled, it would seem easier for paraplegic individuals to find employment.

Further revelations came from statements made regarding the counselling supplied by the labor office (Arbeitsamt), and from the employer's liability insurance associations (Berufsgenossenschaften). Among the reha-population approximately 60% had been counselled during their time in hospital, 8% refused counselling. Those patients projecting vocational rehabilitation measures were counselled in 97% of cases and non refused counselling. Patients planning to return to previous employers used counselling in 46% of cases and only 5% were not interested in conversations with official representatives. Among patients with no commitments for future vocational development (group III) 27% refused counselling and as many as 35% decided not to participate in vocational rehabilitation programs. As the entire rehabilitation-population has been considered to be suitable for vocational rehabilitation programs, in our opinion fewer patients are being counselled than was feasibly possible. Among patients in the rehabilitation-population ($n=651$) only 1.2% entered vocational rehabilitation programs directly after discharge from hospital. In former years paraplegic individuals commonly started vocational rehabilitation immediately after primary clinical therapy; this has become an exception. It appears necessary to allow patients more time to rationalize existential and psychological problems. It has been shown to be advantageous to leave a time interval between medical treatment and vocational rehabilitation in order to give patients an opportunity for social reintegration and to allow sufficient time for compensating grief and sorrow.

Living conditions

Further emphasis in our social statistics was focused on the living conditions of hospital-discharged patients. The evaluations were done on the basis of the total surveyed population ($n=2000$). Forty-seven percent of patients move into housing adapted to the requirements of the disabled individual, 13% move into housing that is in the process of being adapted. Nineteen percent must take up housing that is not suitable for the disabled, while only 5% of patients are admitted for long-term care in nursing homes. Such decisions are determined by the age of the patient and severity of lesions, lack of family support also playing a major role.

Care taking

Of the total surveyed population of 2000 patients, 50% are considered to depend on continuous care taking support. In the majority of cases (73%) these services are supplied by family members. In 40% of cases supplemental support is granted by professional home-care taking organizations, in 8% of cases conscientious objectors serving alternative (non-military) services are involved in care taking of the paraplegic individuals.

Whether the implementation of the National

Disability Care Insurance Law (Pflegeversicherungsgesetz) (effective date 4/1/96 and 7/1/96) will result in a change in this respect will have to be determined by a long-term investigation.

As most care taking is accomplished by family members, it seems necessary to improve the corresponding support services and to offer adequate assistance in order to minimize the enormous physical and psychological burden involved.

Conclusion

By means of the social statistics of the social services in German medical rehabilitation centres for paraplegic individuals we intended to determine the reason for the steady decline in demand for vocational development programs offered by the German vocational rehabilitation centres.

The surprisingly high proportion of individuals resuming work at a previous job or continuing school or studies, amounting to 45% of those surveyed, suggests that there is a general public readiness for reintegrating those with paraplegia in their accustomed social environment. Reintegration is favored by recent

technological developments. The use of commercial data processing equipment enables such people to achieve similarly at the job as nonhandicapped individuals.

Vocational rehabilitation measures at centres offering such programs are in much lower demand by patients at higher age, age 30 already seems to be a critical break point. Married patients are even less inclined to consider vocational rehabilitation measures – 86% of participants of such programs are unmarried.

Disappointingly, our survey also revealed that in many cases appropriate counselling of paraplegic individuals by the responsible public services had not been accomplished.

More precise statements on the demand for vocational rehabilitation programs, care taking services, and appropriate living quarters for the handicapped could be made by the social services in the German centres by starting an on-going data acquisition program. The resulting statistics could then serve to increase the pressure on responsible political parties in order to close existing gaps in the social services for those who are paraplegic.