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SPECIAL REPORT

WEBREHAB: A SWEDISH DATABASE FOR QUALITY CONTROL IN REHABILITATION

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Background: The healthcare sector needs to deliver evidence-based care and be cost-effective. This can be monitored in part via a national quality registry containing individualized data concerning patient problems, medical interventions, outcomes of treatment, and patient-reported outcomes. With this aim, WebRehab Sweden was launched in 1997 and has been available online since 2007. The aim of this paper is to discuss the design, some results, and possible use of such a registry.

Methods: Data entered into the registry online since 2007 were used in this paper. The registry contains information from 7,458 patients. Data from the first 3 years were used to show differences between genders and among diagnostic groups. Non-parametric statistics were used to analyse the differences between groups.

Results: The registry coverage of the country is 95%, and completeness is 81%. Data from hospitals/units have been accessible to the general public since 2009, but no data from individuals can be accessed. Length of stay has varied over the years, becoming significantly shorter between 2007 and 2012.

Conclusion: A quality registry presents an opportunity to improve rehabilitation processes at participating units, provides data for use in benchmarking between units, and enables hospital management to utilize resources wisely.

Key words: quality registers; ICF; rehabilitation.

INTRODUCTION

A discussion of the need for quality assurance and outcomes began in the 1970s (1), when the requirement for national registers was also stressed. In Sweden, the history of national quality-control registers started during this decade (2), with the primary aim being to generate information that could improve healthcare for the patient. The goal of the registers is to become tools for continuous quality improvement and to support a high and consistent quality of care throughout Sweden, ultimately ensuring that patients benefit from the best possible care. To our knowledge, national quality registers in rehabilitation are not in use elsewhere. Monitoring the healthcare process has become an important part of quality assurance, such as via the Commission on Accreditation of Rehabilitation Facilities (CARF).

The healthcare sector must be evidence based and cost effective, given increasing awareness that the resources available are limited (3, 4). This approach includes a consideration of the changing patterns of use of hospital resources, which include a decrease in the mean length of stay and a shift in the focus of care from the hospital to the home or nearby community centres. Another trend in healthcare is a movement towards more individualized treatment, and the participation of the patient in the decision-making process is of increasing interest (5).

To support such challenges, increasing emphasis is also being placed on the use of standardized patient-reported outcome (PRO) instruments. More recently, there has been a move to gauge a patient's subjective experiences of the healthcare provided (6, 7). Today, the Swedish definition of a national quality registry states that it should contain individualized data concerning patient problems, medical interventions, and outcomes after treatment within all areas of healthcare.

The vision for the quality registries in Sweden today is to create an overall knowledge system that is used actively on all levels for continuous learning, quality improvement, and management of healthcare services. There are approximately 100 registries and 6 competence centres that receive central funding in Sweden within a decentralized model, e.g. each register is governed by a professional collaboration. The gathering of information for quality control is regulated by a 1998 Swedish law on data on personal particulars (8), which states that the person has to grant permission for their data to be collected.

The Swedish Society of Rehabilitation and Physical Medicine started a quality register in 1997 for inpatient monitoring and another one for pain rehabilitation (9), which was based on paper registrations that were later entered into a computer and analysed once per year. Despite these efforts, the register never gained popularity, partly due to the slow process involved, which made it difficult to use in everyday clinical quality work.

In 2007, the web-based database WebRehab Sweden (10) was launched as a tool for the continuous quality improvement of rehabilitation in Sweden. The Swedish Quality Register for Pain rehabilitation (SQRP (9)) is also now web-based and there is continuous co-operation between the 2 registers. There are a number of publications pending from the latter (11–13).

The aim of WebRehab is to support a high and consistent quality of rehabilitation throughout Sweden. This goal may be achieved by: (*i*) improving the quality of the rehabilitation process, (*ii*) improving the use of limited resources, (*iii*) enhancing awareness of the International Classification of Functioning, Disability and Health (ICF) model, (*iv*) supporting participating units in developing their rehabilitation process, and (*v*) making comparison between units possible. The register also aims to gather knowledge on rare conditions and to include data that can be used for research. The aim of this article is to present the design, some results, and the possible use of a quality register for rehabilitation.

DESIGN AND STRUCTURE

The database is owned by the Region Västra Götaland and is run in cooperation with Society for Rehabilitation Medicine (which founded the database). The Swedish Association of Local Authorities and Regions (SALAR) has a coordinating function for all quality registers in Sweden and handles funding for the registries, which is sought via competition. WebRehab receives funding from SALAR, and the participating units also pay a small fee. Yearly reports are sent to the participating units and to SALAR, and the data are available to the public via the website. The quality register is monitored by the Uppsala Clinical Research Center, which is a Center of Excellence for National Quality Registries under the National Board of Health and Welfare. The register is open to all entities engaged in rehabilitation. The register can be used to meet the requirements of the CARF regarding knowledge of the patient population as well as outcomes. Since 2009, the results have been accessible to the general public on the internet, with the hospital or unit name clearly stated; however, no data from individuals can be accessed. There is an inpatient module and an outpatient module.

The technical platform OpenQreg is used. This platform can receive data via the internet or from other databases and electronic health records. OpenQreg is also in direct contact with the population register for immediate access to personal data (mailing addresses and deaths). The system is based on the relational database MySQL, business logic written in Java code, and presentation skills with JSP and HTML. In Sweden, strong authentication is required when accessing personal information over open networks. This issue is addressed by an E-Card service, which provides a physical and electronic identification document for each person and is implemented in WebRehab.

The quality register WebRehab can be used for research, but how it can be used is regulated by Swedish law. Applicants have to have approval from the Regional Ethical Committee and then apply for approval from (and submit a research plan to) the registry before data can be extracted.

Data are entered online and are immediately accessible. The main aim of the registry is to facilitate quality improvement in rehabilitation settings and to follow the process from the rehabilitation period after injury, with admission and discharge, to follow-up 1 year after the onset of illness/injury. Comparisons of a patient's results with the results from the hospital, as well as with national results, are possible. Data on the patient level are available only within the entering unit (anonymous for all other units). Data from the unit can be exported to Microsoft Excel®. After the main diagnostic code is entered into the database, there are 4 modules that the programme selects from, depending on ICD codes: stroke, brain injury, spinal cord, and other. The ICD codes are combined into 17 diagnostic groups: Stroke, Subarachnoid haemorrhage (SAH), Traumatic brain injury (TBI), Post-infectious/post-inflammatory brain damage, Anoxic brain damage, Other brain damage, Spinal cord injury, Demyelinating diseases, Other neurological diseases, Rheumatoid arthritis and inflammatory diseases within the muscular-skeletal system, Rehabilitation after orthopaedic surgery or trauma and other diseases within the muscular-skeletal system, Amputations, Heart, Vascular or Lung disease, Cancer, Psychiatric illness, Other trauma, and Other diseases. In the annual report, only the most common groups are reported, as follows (because many only contain few individuals): (*i*) Stroke; (*ii*) TBI, SAH, or Other brain damage; (*iii*) Spinal cord injury; (*iv*) Demyelinating diseases and Other neurological diagnoses; (*v*) Other trauma/diagnoses in the muscular-skeletal system; and (*vi*) the rest.

Demographics. Information on referral patterns, number of registrations, civil status, employment, diagnoses, problems according to the ICF (14), height, weight, use of tobacco, alcohol abuse, and illicit drug use, among others.

Process measures. Time from referral until admission; resources; time of care; whether questions on tobacco, alcohol, and drug consumption have been asked; setup and usage of a rehabilitation plan; whether assessment of driving has been performed; and use of different assessment instruments at the unit.

Outcomes. Deceased during the period; Activities of Daily Living (ADL) level before and after rehabilitation using the Functional Independence Measure (FIM™) (15); complications; medical incidents; household and work before discharge, at discharge, and one year later; where the person is discharged to; life satisfaction; and if the rehabilitation plan has been used. Dependency was defined as being dependent in one or more of the different items either of the 2 subscales of FIM™.

Patient-reported outcomes (PROs). Glasgow Outcome Scale Extended (16, 17) as an interview to gauge the patient's perceived symptoms, EQ5D to gauge health-related quality of life (18), and life satisfaction according to Fugl-Meyer (Li-Sat) (19). To assess the patient's perception of his or her situation

after living in the community, the Impact on Participation and Autonomy (IPA) (20) is used.

Patient satisfaction. Satisfaction with the staff; cooperation with the staff and the rehabilitation plan; own influence on the rehabilitation (including the individual rehabilitation plan); and satisfaction with the information and treatment that family and next of kin have received during the rehabilitation; information about the disease/trauma; and information about where to turn if support after discharge is requested, were graded by the patient or next of kin on a 5-point scale.

Which patients to register is decided locally, and the data gathering is often divided among different people (professions), but the NIHSS is administered by physicians. The most important aspect is to ensure that someone is responsible for ensuring both that patients are assessed for PROs as well as patient satisfaction. The data in the register can be organized according to the ICF domains (Fig. 1).

MATERIAL AND METHODS

From 2007 to 2012, more than 16,000 entries for inpatient rehabilitation were entered into the registry, and yearly reports were generated with descriptive statistics. Length of stay was assessed each year. Since the registry became web based, these reports have been available online. Data from the first 3 years, including information from 7,458 patients, are used to show differences between genders and diagnostic groups in this paper. Non-parametric statistics were used (χ^2 test) to analyse the differences between groups. A significance level of $p \leq 0.05$ was accepted as indicating significance. For statistical calculations, the programme SPSS 19.0 was used. Completeness was assessed by determining the number of patients treated over the last year at each participating entity, based on the hospital database. This number was compared with the number of complete files in WebRehab.
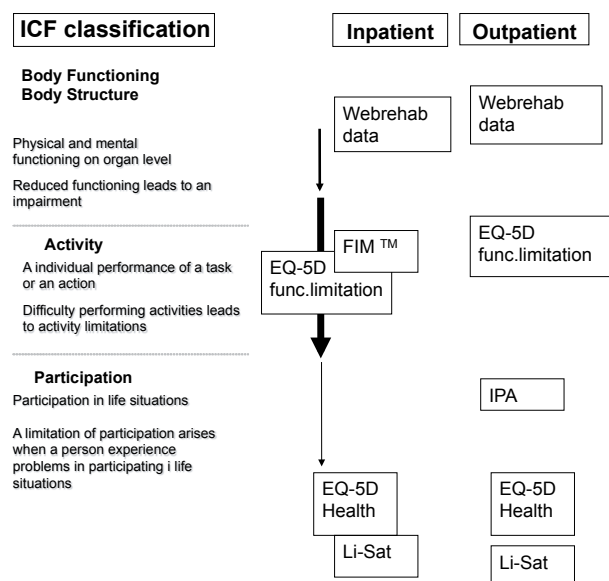

Fig. 1. The data in the register, presented according to the International Classification of Functioning, Disability and Health (ICF) domains and the data for inpatients and outpatients. IPA: Impact on Participation and Autonomy; EQ-5D: EuroQuol in 5 Dimensions; FIM™: Functional Independence Measure; Li-Sat: Life Satisfaction according to Fugl-Meyer.

RESULTS

Twenty of the 21 counties/regions (95% coverage) in Sweden (25 different units) participated in the register (2012). At the start of 2007, coverage was approximately 75% (15 units). Completeness (the number of cases available that have been completed) was 81% on average (ranging from 46% to 100%, with 3 units below 60%) as of 2011. This value was much lower at the start. Rehabilitation medicine units are the most frequent contributors (focused on patients of working age, 16–65 years), but, 4 units are mixed rehabilitation medicine and geriatric units (above 65 years of age).

From 2007 to 2012, there was an increase in registrations (an increase of 118%) (Fig. 2). The number of performed 1-year follow-ups increased from 1,419 in 2009 (which was the first year) to 1,711 in 2010 and to 1,799 in 2011. The mean age was 55.8 years (SD 16.4), and 33% were above 65 years of age.

The most common cause of inpatient rehabilitation is stroke (approximately 700 per year), followed by TBI and other brain damage (approximately 400), meaning that acquired brain damage (combining all causes) accounts for > 55% of all entered data. However, not all data from patients receiving inpatient rehabilitation are entered. In addition, certain units enter data at admittance, but fail to complete discharged data, and not all have complete datasets.

Problems noted

Different problems are noted for different patients using the ICF (14). As an example, in the area of "sensory function and pain," problems are most commonly acknowledged for patients with spinal cord injuries. Frequent problems are impaired sensibility; pain in the back, neck, and extremities; and impaired proprioception. People with brain damage commonly have problems with vision (seeing functions) as well as headaches (pain).

Gender differences

More men than women have been rehabilitated as inpatients (59% men compared with 41% women in 2010 and 2011 and 57% compared with 43% in 2012). Whether this is a real change will have to be assessed in the future.
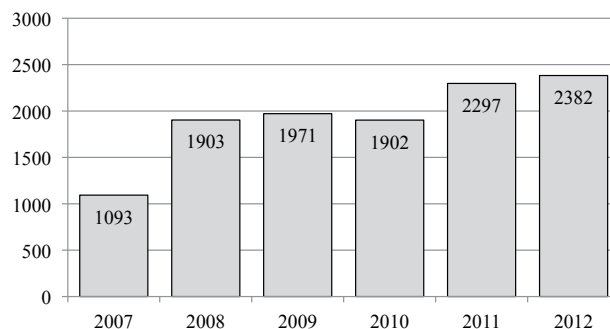

Fig. 2. Number of people discharged with complete data in different years. On the X axis the different years are presented and on the Y axis number of patients discharged.

Men are the majority in the diagnostic groups of stroke, TBI, spinal cord injuries, and other neurological disorders. In SAH, demyelinating disorders, rheumatic disorders, and rehabilitation after orthopaedic surgery, women are the majority.

Nutrition and drugs

Nutrition is an important quality indicator, and body mass index (BMI) can be used as a surrogate measure of this indicator. These data have not been provided by many units, and there has been discussion regarding the importance of this measure, at the annual meetings as well as in the reports. Nevertheless, the percentage has increased from 81% to 83% at discharge. The different units are encouraged to follow this protocol for the individual patient. So far, changes in BMI have not been investigated in the annual reports. As for the other parameters, certain units are better in registration, and several are worse.

There was a difference between the diagnostic groups regarding history of smoking and abuse of alcohol and illicit drugs. The group of patients with TBI were alcohol abusers (27%, $p < 0.001$) and users of illicit drugs (7%, $p < 0.001$) significantly more often than were people with SAB or stroke. In Sweden, 13% of the general population is said to have risky drinking behaviour. Smoking was more frequent ($p < 0.001$) in patients with SAB (30%) and TBI (30%) than in patients with stroke (20%). These percentages are much higher than the reported 13% of the Swedish general population.

Length of stay and dependency

The median time between acceptance for rehabilitation and admittance was 6 days. The mean length of stay varied over the years, but was significantly ($p < 0.001$) shorter in 2012 (39 days) than in 2007 (50 days). One unit has had a much longer length of stay than the others. Length of stay also varied in the different diagnostic groups. During the first 3 years, the patients with SAH (297 patients, 62 days) or TBI (580 patients, 63 days) had significantly longer lengths of stay than did patients with stroke (2,293 patients, 37 days). This difference was not observed in 2012 (mean of 40 days for 872 stroke patients and 40 days for 475 SAH and TBI patients). No significant difference was observed for gender. Length of stay was shorter for people above 65 years of age as well as for those with obesity (BMI > 30), although the difference was not statistically significant.

Dependency can be assessed both at admittance and at discharge. The clinic with longer lengths of stay for stroke patients had the same average FIM at admittance and at discharge as the other clinics. The average dependency in motor FIM items for all of the patients at admittance was 85%, and the percentage was 62% in social/cognitive items. At discharge, dependency was lower: 62% in motor items and 48% in social/cognitive items. Changes in the percentage of dependency can be considered as a measure of efficacy. Data have also been analysed for the stroke group, in which rehabilitation resulted in a reduction in dependency in motor FIM items, from 87% of the patients to 61% at discharge.

Use of process measures

An assessment to determine suitability to drive was performed in 91% of all patients at discharge. However, there was large variation among the hospitals (0–31% not being assessed), so this area has been suggested as a focus for on-going quality improvement. BMI was calculated for 87% at admittance and for 81% at discharge, which is a slight improvement compared with 2009. Again, there was large variation among the hospitals (44–100% at admittance and 31–100% at discharge). A written rehabilitation plan was provided for > 90% of patients. However, less than 70% received this plan at 2 hospitals (of which 1 seems to not have issued a single plan).

Results for PROs and patient satisfaction

According to the EQ5D, all 5 domains improved, with a higher percentage indicating no problems. As an example, at discharge, the domain anxiety/depression changed from 40.6% to 55.7% for "no problem," and "severe problems" decreased from 6.3% to 3.6%. Usual activities and pain/discomfort were less frequent at discharge from inpatient rehabilitation. There was also improvement in the VAS EQ5D (14 units) from admittance to discharge for inpatients and outpatients.

From admittance to discharge, for outpatients, the "Impact on participation and autonomy" questionnaire showed improvement regarding independence indoors, the role in the family, independence outdoors, and work/studies. The area regarding social roles (including intimacy) showed no change during this time.

Patient satisfaction

Patient satisfaction (in 2011 and 2012) was high, but there was missing information for more than 40% of the entries. The percentage of entries of "dissatisfied/very dissatisfied" ranged from 2% to 4%. The 2 problematic areas were the patient's own influence on the rehabilitation (including the individual rehabilitation plan) and information about where to turn to if in need of support after discharge; 4% of entries in both cases were "not satisfied."

DISCUSSION

The aim was to launch the register and improve quality in rehabilitation. What can be said after more than 7 years of use? The online registration is working. However, not all units realize that quality registration takes time, and time does not seem to be allocated in sufficient amounts, and it is clear that not all entries are completed (partially or completely lacking discharge data). With electronic medical records, one would like to have the opportunity to link data immediately, but this linkage is still not possible. There is also room for improvement in the 1-year follow-up, probably due to logistic problems and ethical considerations. Time first has to be given to staff to perform a follow-up; a plan is needed if the follow-up identifies problems that need to be addressed. It seems as if the register is still not used to its full potential by hospital management in many cases.

The local authority responsible for 1 unit with a longer mean length of stay for patients had an external audit performed. The result, showing that patients with stroke had a longer length of stay, but had the same level of dependency at admittance and at discharge, was not known by the head of the clinic or the hospital, despite the data being published and sent to the clinic. The cause of the low efficiency was explored. The audit noted that the ward was run by inexperienced physicians who did not have sufficient support from the clinic leadership. This issue has been described as a target for improvement, and the local authorities will follow-up on the results over the next year. This situation shows how the database can be used for clinical improvement as well as for external audits.

There is room for improvement in the data covering the rehabilitation process; there are not enough registrations on BMI, which can be used as a measure of the quality of care. Sexual problems are often not addressed. Rehabilitation plans are not always set up, but when they are present, the plans are used. Patient satisfaction with the rehabilitation delivered is high. However, there is room to increase the influence of the patient on the rehabilitation and the rehabilitation plan, which can improve patient satisfaction. Dissatisfaction regarding knowledge of where to turn to after discharge might reflect the complexity and on-going alterations in primary care in Sweden. This uncertainty about where to go for primary care is not so easy to solve for the inpatient unit providing rehabilitation because many patients do not have prior contact with the primary care system. Improvement in quality of life and autonomy most likely takes longer than does the time in rehabilitation (21) because this improvement also includes adaptation to the new situation.

The SALAR's aim for open comparisons is to stimulate counties and cities to analyse their services, learn from others, improve quality, and work more efficiently. The citizens in a democratic society have the right to obtain full information on tax-financed services to see how their money is spent. This openness has caused a discussion in the newspapers of acute care for myocardial infarction in Sweden, where there has been gender variation in treatment (22). The same discussion will most likely occur regarding the regional differences in thrombolysis for acute stroke (23).

A quality register presents an opportunity for an improved rehabilitation process at the participating unit, for use of the data for benchmarking between units, and for hospital management to utilize resources wisely. In a system in which healthcare is tax-financed and no real competition occurs among hospitals, quality registers are also needed. One benefit of this system is the possibility of openness of data at the hospital level, which gives legitimacy to the process.

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