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A computer assisted follow up system for spinal cord injury patients

R Levi MD, C Hultling MD, N Westgren RNM

Solberga Project/Karolinska Institute and Centre for Neurotraumatology, Karolinska Hospital, Stockholm, Sweden.

The comprehensive care of patients with traumatic spinal cord injuries (SCI) necessitates, among other things, a structured, life-long follow up. The high consumption of medical care in chronic SCI patients, often a result of diseases affecting many different organ systems, soon causes the cumulated medical documentation to be extensive and therefore hard to survey. The possibilities for rational patient management, adequate quality assurance, and clinical research may improve considerably by computerisation of medical records. A computerised medical records system for SCI has recently been developed, using a semistructured medical record format for data input and a medical entity dictionary for facilitated data storage and retrieval. The principles for developing this computer-assisted follow up system are described.

Keywords: computers; outpatient care; spinal cord injuries.

General considerations

Computers are already widely used in medicine. Computerised medical records and administrative routines can save both time and money, as well as facilitate statistical analysis, quality assessment and research in the clinical setting.[1–4]

Many computerised medical records and administrative systems are available on the market. In order to make an optimal choice, the individual care provider must be able to clearly define his specific clinical and scientific demands on such a system. Many of the current commercially available systems have been created with the general practitioner in mind. Priority in these systems is usually given to speed in input and retrieval of information, as well as to various administrative functions. This matches the high patient volume load in general primary care, with frequent and short contacts. Also, because of the marked heterogeneity of medical problems confronting the general practitioner, systems intended for this segment of medicine are usually based on free text, rather than pre-structured medical records. Further, the demand for statistical and scientific processing of data in family medicine is still usually limited, which again is reflected in the restricted capacity of many computer systems.

In contrast, specialist care such as that provided by SCI systems of care, usually deals with smaller patient volumes and a much more homogeneous set of problems. The demand for data processing for scientific purposes is usually high. Thus, a high degree of structure in the medical records is both desirable and indeed necessary. This makes many commercially available systems less suitable for those working in the field of SCI.

This article describes a commercially available computerised medical record and patient administration system, which was chosen based on the needs of a research-oriented specialist outpatient clinic, and was then customised to fit the specific demands of care for spinal cord injured (SCI) patients.

The regional SCI outpatient clinic in Stockholm

The first centralised regional SCI outpatient clinic in Sweden was established during 1991–1993 by the Solberga SCI Research Project in collaboration with the Neuro-

Correspondence: R Levi, Solbergaprojektet/Karolinska Institutet, S-126 91 Stockholm, Sweden.

trauma Centre at Karolinska Hospital in Stockholm. By using all available sources, approximately 400 patients with traumatic SCI were identified in a population of 1.5 million, comprising the Greater Stockholm area. All patients were contacted and later invited to the clinic for a comprehensive clinical evaluation. The data were recorded in semistructured protocols (Table I). Previous medical records, supplementing the patient interviews, were utilised for a thorough description of past medical history, including details of acute care for their SCI. The current medical situation was then studied, using checklists for organ system functions, including common problems such as pain, spasticity, incontinence, sexual dysfunction, late neurological deterioration, as well as a general systems review. Physical examination included neurological classification according to ASIA/IMSOP standards,[5] and general medical status. Routine blood and urine chemistry were performed.

This database represents the fundamentals of the clinic, which then operates by prescheduled annual visits, as well as additional contacts on an 'as-needed' basis for specific problems, by initiative from the patient and/or care provider.

At an early stage it became apparent that computerisation would greatly facilitate everyday work, as well as data processing for clinical research. Creating a computerised medical record system from the start was initially tried, but proved to be impractical both for financial and logistical reasons. Instead, all commercially available systems in Sweden were reviewed in the light of the specific demands for this branch of medicine (see above). In particular, the following points were given high priority:

- ability to create prestructured records ('check-lists');
- ability to easily retrieve information from the total patient population as well as for defined subgroups or individual patients, for statistical processing;
- professional secrecy, e.g. possibility to define different levels of access to the data base for different staff groups;
- user-friendly system, minimising costly and time-consuming education of staff.

We found that a Swedish system called MacAdapt, based on Macintosh hardware,

Table I Representation of initial survey of SCI outpatients. Actual records comprise over 50 pages, due to semi-structured 'checklist' design. This data base was then converted to computerised medical records as is described in the article

SCI specification
- Aetiology
- Time of injury
- Spinal column lesion
- Spinal cord lesion
  - ASIA classification
  - FIM
  - Time and place for hospitalisation
  - Acute treatment
- Associated injuries
  - Acute treatment
- Complications
  - During initial hospitalisation
  - After discharge until present

Previous medical and psychiatric conditions

Current medical situation
- Neurological deterioration
- Pain analysis
- Spasticity analysis
- Urological function
- Bowel function
- Sexual function
- Systems review
  - General
  - Eye
  - ENT
  - Gastrointestinal
  - Respiratory
  - Cardiovascular
  - Musculoskeletal
  - Neurological
  - Psychiatric

Current psychosocial situation

Current medication

Physical examination
- Anthropometric data
- Systems review (see above)
- ASIA classification
- FIM

Quality of life assessment

Blood/urine chemistry

AISA = American Spinal Injury Association, FIM = Functional Independence Measure, ENT = ear, nose and throat.

best matched our specifications. (Since 1991, when this survey was made, several other commercial systems have been developed, which fulfil these criteria. To our knowledge, however, none has so far proved to be substantially superior in these respects).

The MacAdapt medical record and patient administration system

MacAdapt is based on a so-called 'medical entity dictionary'. All items of information that can be represented by a given entity will be labelled and identified accordingly. For example, elevation of blood pressure could be expressed as 'hypertension', 'high blood pressure', 'hypertonia', 'arterial hypertension', etc., according to the linguistic preferences of the individual health care provider. This would obviously create problems when asking the computer to perform a free text search. Instead, all these expressions will be defined as being synonymous with, for example, 'hypertension', and therefore will all be identified by this specified entity. Thus, the major 'building blocks' of information contained in the medical record, will be found in the medical entity dictionary.

These building blocks can then be combined in various structures or check-lists. Such checklists are stored by the computer, and can be retrieved for guiding medical history and physical examination during, for instance, annual check-ups (Fig 1).

In addition to the medical entity dictionary, information regarding patient identity (i.e. name, address, social security number), and information regarding clinic contacts (i.e. data, caregiver, type of contact) are stored separately. These three information banks merge in a so-called medical event. Here, the interaction between patient and caregiver at a certain time is described and leads to implementation of the medical entities in terms of descriptive text, measurements, diagnoses, procedures,

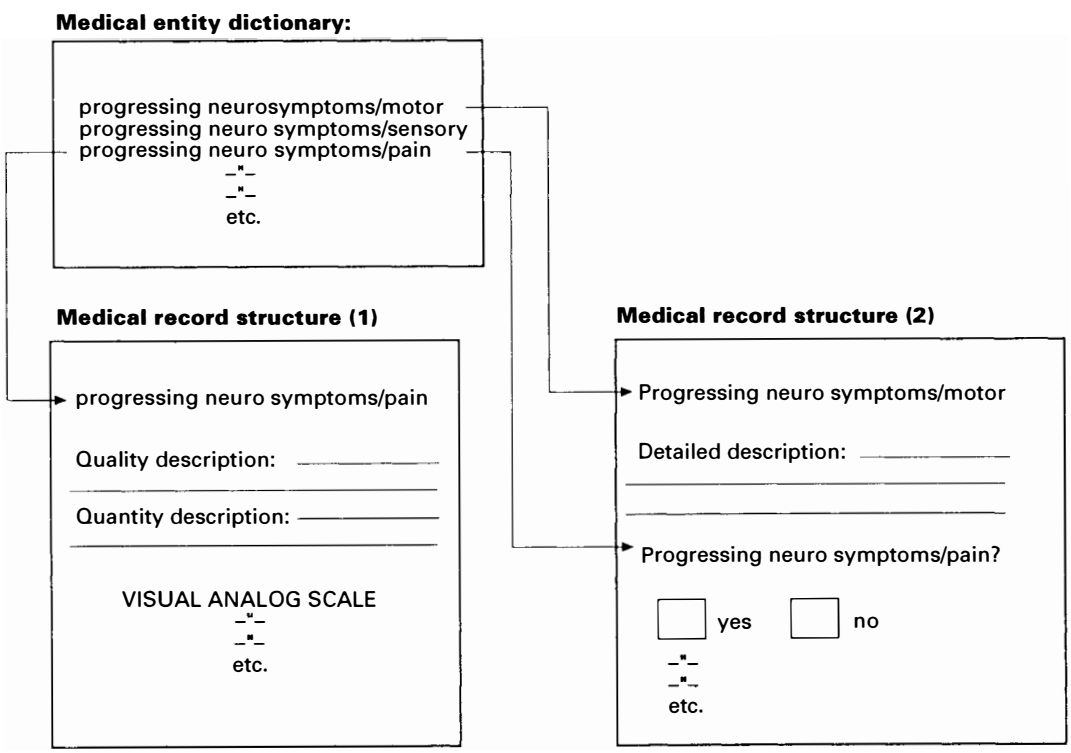

Figure 1 The major 'building blocks' of information are found in the medical entity dictionary and can then be combined in various structure or checklists, as exemplified in this figure.

prescriptions etc. The object 'contact' contains the administrative setting in which the medical event occurs.

The cumulated medical events thus make up the medical record (Fig 2).

Customarisation of MacAdapt for SCI outpatient care

The panorama of the most common and/or serious potential complications in SCI is well known among those working with SCI patients. In addition, the incidence and prevalence of such complications have been determined in several studies. Taken together it forms the basis for design of follow up programs. Since many complications proceed inconspicuously, giving few symptoms and appearing at any time post injury, early diagnosis and treatment requires regular evaluation, with particular focus on preventable and/or treatable diseases and functional impairments. Thus, the follow up should serve as a screening programme for a given high risk population, i.e. SCI patients. We therefore found it desirable to create a system of prestored medical record structures. Such structures then serve as checklists at each visit (Fig 3). The risk of neglecting or disregarding crucial issues when taking the history or performing the physical examination will thus be minimised. In addition, the clarity of the medical record, as well as the possibility for comparison with previous results, greatly improves. On the other hand, clinical medicine provides a wealth of relevant information, that is difficult to incorporate in a

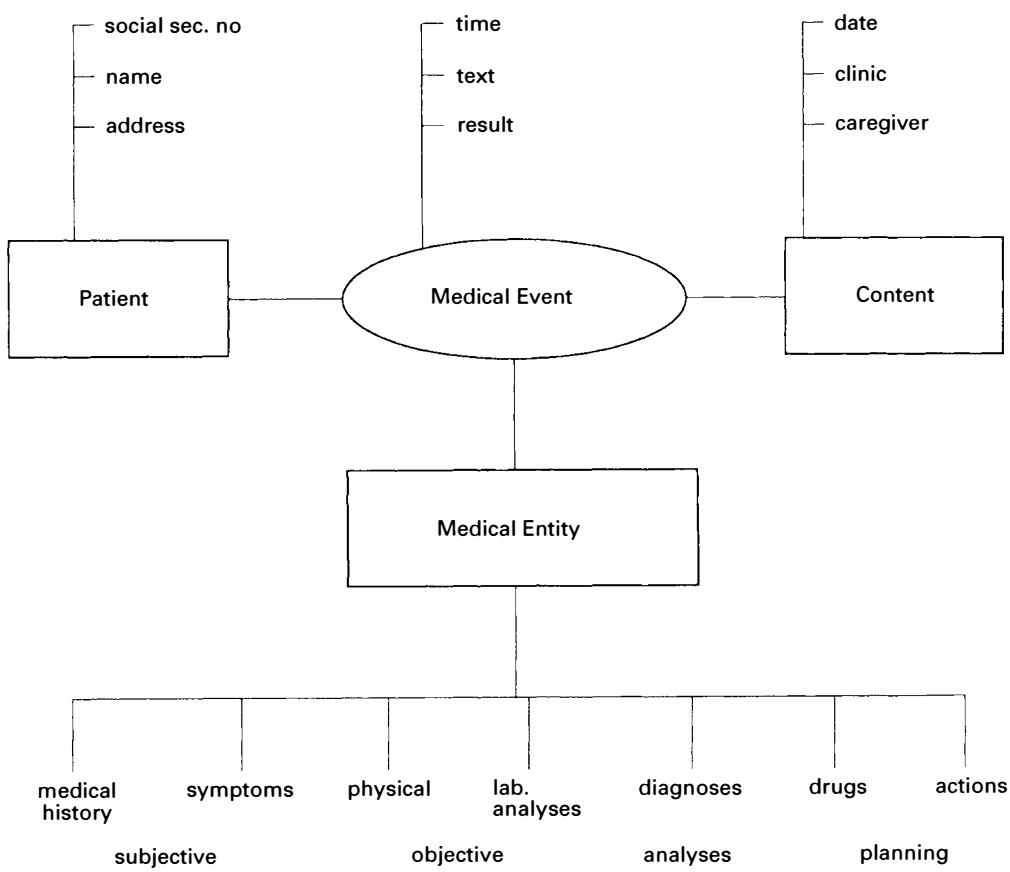

Figure 2 The medical entity dictionary, together with information regarding patient identity and information regarding clinic contacts, merge in a medical event. The cumulated medical events make up the medical record.

PRESENT MEDICAL CONDITION

a. Progressing neurological symptoms

- loss of motor function?	no	☐	yes	☒
- loss of sensory function?	no	☐	yes	☒
- pain?	no	☐	yes	☒
- spasticity?	no	☒	yes	☐
- autonomic dysreflexia?	no	☒	yes	☐
- hyperhidrosis?	no	☒	yes	☐

Figure 3 A system of prestored medical record structures serve as checklists for each clinic visit. Here an example of such a structure is shown.

totally prestructured format. Therefore we utilised the possibility of additional, unlimited free text storage. The resulting format can therefore be defined as semistructured (Fig 4).

The causes for contacts on an 'as needed' basis are innumerable. For this reason free text notes may be preferable to prestructured records in such instances. Free text can be searched for as such, but the risk of omissions is great because of variations in nomenclature, misspellings etc. Therefore we summarise all events recorded as free text during the year, in the next annual check-up scheme once the patient arrives for that session. The essence of the free text information can at that stage be incorporated under the various medical entities comprising the checklist, and thus be made more easily searchable.

Inevitably, the care of SCI patients requires involvement from many different medical and paramedical specialists. Not all of these professionals will be familiar with all the nomenclature and definitions used in SCI care. Therefore, clarification of the terminology has been provided by addition of explanatory entity-related phrases to the prestored medical record structures. These phrases are automatically included in printouts of the medical record, thus facilitating communication with patients as well as with other care providers (Fig 5).

Finally, communication between different SCI centres requires uniform classification. This was achieved by incorporating the ASIA/IMSOP classification of SCI in the medical entity dictionary. Thereby, every patient is classified in a standardised way regarding neuroanatomic and functional parameters.

Concluding remarks

Modern SCI care should include a life-long, structured follow up. The basis of such a follow up programme is provided by planned outpatient visits annually or every other year, supplemented by additional contacts for specific problems, initiated by the patient or care provider. The relative homogeneity of this patient group, as well as the predictability of certain functional impairments and complications, makes it feasible to apply a high degree of structure to medical records. Such structure serves the dual purpose of providing check-lists for clinical care, as well as a basis for research and quality assessment. Computerisation of medical records is now a general trend in medicine. Our preliminary experience with the implementation of computers in outpatient SCI care is definitly a positive one. In particular, by storing information in a medical entity dictionary, retrieval of data for statistical and research purposes has been substantially facilitated. Admittedly, the initial efforts needed to launch such a comprehensive computerisation, are formidable. Obvious problems arise, for instance, in the transitional period, when large amounts of information from old case

PRESENT MEDICAL CONDITION

a. Progressing neurological symptoms

- loss of motor function? no [ ] yes [×]

If yes, specify: *Complete loss of C6 motor function in left hand for 6 months*

- loss of sensory function? no [ ] yes [×]

If yes, specify: *Complete loss of C6 motor function in both hands for 6 months.*

- pain? no [ ] yes [×]

If yes, specify: *Increasing burning pain in both hands for 8 months.*

- spasticity? no [×] yes [ ]

If yes, specify:

- autonomic dysreflexia? no [×] yes [ ]

If yes, specify:

- hyperhidrosis? no [×] yes [ ]

If yes, specify:

Comments re progressing neurological symptoms:
MRI January 1994 showed spinal cord extending from level of lesion at C8 up to C5/6 disc space. The cyst distends the spinal cord at C6–C8 levels.

Figure 4 The possibility of additional, unlimited free text storage is utilised, making the resulting format semistructured.

records must be converted to the computer medium. This task can prove to be demanding both for secretaries and physicians. Furthermore, it is absolutely necessary to have a good working relationship with computer programmers and software as well as hardware providers, as many unforeseeable problems are bound to occur. The costs involved in developing a tailor-made computerised system are substantial. In Sweden, our pilot system is the first in this field of medicine. Based on our experiences and others, consensus will hopefully be reached as regards a standardised computer system

Neurological level of injury (NLI): *C5*

NLI = The most caudal segment of the spinal cord with normal sensory and motor function on both sides of the body.

ASIA Impairment Scale: *C*

C = Incomplete. Motor function is preserved below the neurological level, and the majority of key muscles below the neurological level have a muscle grade less than 3.

Neuroanatomical Syndrome: *Central Cord Syndrome (CCS)*

CCS= Central Cord Syndrome. A lesion, occurring almost exclusively in the cervical region, that produces sacral sensory sparing and greater weakness in the upper limbs than in the lower limbs.

Figure 5 Clarifications of terminology are provided by addition of explanatory entity-related phrases to the prestored medical record structures.

for all SCI clinics, at least nationally. This would make both costs and efforts for subsequent installations much less demanding.

Finally, it is always difficult to change work habits. The transition from the use of pen and dictaphone in a free and sometimes totally individual style, to the quite standardised and restricted documentation by use of computer, is met with understandable apprehension by some collegues (and patients as well). Nevertheless, we feel that computerisation will ultimately benefit SCI care and research substantially.

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