

Editorial

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Paradoc: an electronic ‘turntable’ towards information on spinal cord lesions

ParaDoc (PDc), URL: ‘<http://www.paradoc.org>’ is a relatively new, rapid, and efficient electronic platform that focuses on providing access to information about problems related to traumatic or nontraumatic spinal cord lesions (SCL). This includes medical, rehabilitation, self and community care questions. The main goal of PDc is to facilitate education and training on SCL in developing countries. Its immediate focus is therefore to guide people from these countries to information that is pertinent to their specific question. Nowadays those who have access to it can very easily consult online reference sites and websites are rapidly growing in number. As a result, a web-based ‘turntable’ information platform appears to be a very efficient way to rapidly and effectively distribute large amounts of information to remote locations.

PDc is a joint project of the International Spinal Cord Society (ISCOS), its Education Committee, and the Swiss Paraplegic Foundation (SPF). Since it was launched in early 2000, it has been based at the library of the Swiss Paraplegic Centre (SPC) in Nottwil, Switzerland.

PDc has been presented, demonstrated, and discussed at the annual ISCOS (formerly IMSOP) scientific meetings in Sydney (2000), Nottwil (2001), and Vancouver (2002). Owing to the multitude of regional economic and cultural differences, even in one country, running a project like PDc is quite an endeavour, but we believe that many people will benefit from it. In the following, we will briefly present some of the goals and features of PDc.

PDc’s main goals are two-fold: first, rapid distribution of information on SCL. This is accomplished via providing uniform resource locators (URL’s) to specialized internet platforms world-wide and via literature provided by the library of the Swiss Paraplegic Centre in Nottwil (contact address see below). Second, PDc aims at giving access to downloadable training material on SCL. This material may be saved and used anywhere in the world, in particular, in developing countries, where it may be difficult to obtain relevant information from libraries or other sources. In the following paragraphs, we will discuss some of the information available on PDc.

‘Links to related sites’

These provide URL’s directly to Internet sites with SCL-related information. The list includes international

health organizations and also provides information on national organizations in 26 different countries, including humanitarian, health specialists, and disabled people’s associations. These links are just a limited selection of all available international internet sites and will be further updated in the future.

PDc does not collect key medical, scientific research, or technical literature because this information is readily available to professionals in different databases such as PubMed, Medline, Decline, BMN, etc. Professionals use registered institutional libraries and can obtain documentation. However, on ‘Links to medical libraries’ some direct connecting URLs to a few national university libraries are available. This list cannot be exhaustive, but could provide a starting point for many search tasks.

‘Upcoming events’

Attempts to give an overview of forthcoming international and national conferences and meetings in the field of SCL. The organizers and web pages of these meetings can be reached by just clicking on the given web- or e-mail address. This page is regularly updated, but the quality of the information given strongly depends on the information given to the PDc team in due time.

‘Catalogue’

Leads to the PDc collection of publications: books, booklets, historical articles, and handouts. A great part of this collection is the so-called ‘grey’ literature. Grey literature refers to publications that are not usually listed in catalogues and databases of booksellers; often they are not published by a commercial publisher and therefore hard to find. This grey category includes, for example, internal publications of hospitals that are used as handouts for patients. Most of the listed media are stored in our documentation centre at the library of the SPC in Nottwil.

The catalogue offers various bibliographic search criteria: specific themes and subjects, author(s), title, language, country of origin, or year of publication. For example, a ‘subject’ search yields a list of relevant titles with detailed bibliographical information, on the content, and the source location of the respective document.

The bibliographical information is supplied in English, although the publication may be in another language.

In very difficult situations, where it is not possible to obtain a book or other relevant information locally, one may also contact the PDc library in Nottwil. The librarian will ask you to fill in a short questionnaire, for the records, which will be sent to you via e-mail. After this first contact, any possible help will be made available.

‘Online documentation’

In addition to hard copies of books and other printed documents, PDc also collects online publications. These can be particularly interesting for educational material and handouts, because relatively small documents can easily be redistributed via e-mail. All collected electronic documents currently available from PDc are listed both in the ‘catalogue’ and under ‘online documentation’. The ‘online documentation’ website enables the visitor to directly access and download the desired document. PDc also intends to postprinted publications on its website as either a PDF or HTML format, but this depends on what material is given to PDc and on copyright restrictions. We hope that this will further enhance the usefulness of the site.

‘Historical material’

PDc is also collecting and, if possible, safeguarding historical publications (books, articles, etc) on SCL that were published before 1965. Our present collection, although far from complete, goes back to 1827, by Charles P Ollivier (of Angers). Similar to the regular catalogue, it is possible to search these publications referring to the name of the author and the year of publication through the library’s ‘catalogue’. If the desired publication is not available in Nottwil, the above-mentioned link ‘Links to medical libraries’ will allow you to search these libraries and consult their catalogues. This often entails an identification, password, and eventually cost.

‘Questionnaire’

Recently, PDc sent a questionnaire to the members of ISCOS. Eventually, the questionnaire was sent to 260 addresses; sadly, only 29 came back filled out. In all, 13 responses came from South Africa, Zimbabwe, Korea, Japan, Thailand, Saudi Arabia, Brazil, Turkey, Slovak

Republic, Czech Republic, and Croatia. Occasionally, some difficulties in apprehending the English language (especially in Eastern European, African, and Asian countries) were signalled, mainly among allied professionals and the concerned public.

The questionnaire indicated that in most cases, the sources for information on SCL are Internet and libraries. The most frequently requested informations are on medical literature and information for people with SCL. The formats requested ranged from slides and handouts to printed material including drawings (such as the RSA Ithuseng Manual) or online documents. Access to the Internet is generally not too expensive in Europe or North America, but this is certainly not true for every place in the world. As a result, to our surprise, the range of internet access was between 1 and 60% (!). In some returned questionnaires, it was suggested that handouts be available on a larger basis, in the original language of the country or region, and on cheaply available media. This is of particular importance for workshops and training in many developing countries.

The questionnaire thus points to a multifaceted challenge for PDc: eventually it is necessary to provide information in a way such that the information can be readily distributed even without permanent access to the internet and in a multitude of languages. Our collection of downloadable material may therefore be crucial for places with a low internet access rate, because once the material is downloaded, it can be copied and distributed via mail or other means. However, it also shows that there is a further need for documents in other languages than English.

As a consequence, PDc wishes to collect SCL-related documents for further distribution. In this respect, we are highly dependent on ISCOS, as an international society, on its members, or on others, who wish to volunteer information.

Our task seems to be evermore growing, both on an organizational and a financial level. In spite of being a very small team in number, but certainly not in motivation and energy, we hope to customize the site within the coming months to our main objective: facilitating education and training in developing countries by providing educational and other materials on SCL. The team welcomes, and greatly appreciates, any comments and suggestions from all who wish to join us in our effort.

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