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Title: The development of an information website for patients and health professionals on the bladder, bowel and sexual disorders of cauda equina syndrome.

Aims of Study:

Damage to the cauda equina (the lumbar and sacral nerve roots within the spinal canal and below the conus medullaris) may present either acutely or chronically with varying degrees of bladder, bowel and sexual dysfunction. The symptoms of pelvic organ dysfunction are usually invisible to others, but can still severely affect the patient's quality of life. In addition, other symptoms such as leg weakness, pain and sensory abnormalities are a significant cause of morbidity.

The causes of cauda equina syndrome (CES) can be congenital or acquired and include trauma, medical procedures, haemorrhage, infection and tumours. Patients may therefore present to a large variety of specialists for diagnosis and treatment, including neurologists, neurosurgeons, orthopaedic/ spinal surgeons, trauma surgeons, pain specialists, general physicians, oncologists, paediatricians and urologists. Accordingly, after diagnosis, CES requires multidisciplinary input from numerous medical and paramedical subspecialists. However in practice, once the medical emergency surrounding the cause of cauda equina injury has resolved, the team who care for them, be it orthopaedic or neurosurgical, is unlikely to be able to offer any further support.

Most patients with acquired causes of CES were healthy before their diagnosis and find it very difficult to adapt to life with this disabling and demoralizing condition.

Following discussion with a large CES patient support group, it became apparent that many physicians do not have a thorough understanding of the causes, diagnosis and the need for multidisciplinary management of CES. In addition, it appears that easily accessible and understandable information for patients on the prognosis and management of CES is not widely available. Furthermore, access to specialists and paramedical services varies considerably from region to region.

Therefore we undertook to develop an information site for patients, physicians and other healthcare professionals on the world wide web (WWW), which would be a source of information on CES. Methods

The website is divided into a general information section (for patients, paramedical specialists and physicians) and a literature review section, written for a medical audience, but accessible to all. In order to make the patient information component of the website easily understandable to non-medics, we recruited a team of four patients with CES (3 women and 1 man), 3 of whom are nurses.

The proposed content and structure of the website was discussed with the CES patients, a continence advisor, a representative of the Continence Foundation (a UK continence charity) and a medical librarian with an interest in patient information on the WWW. Technical advice relating to the design and hosting of the website was obtained from experts in medical information on the WWW (Health Media Group, London, UK).

Personal (anonymous) accounts from patients in a large CES support group were reviewed and we

identified particular problems mentioned by the patients (e.g the lack of advice regarding urinary and faecal incontinence). These issues were then addressed in the patient information section of the website. We focused in particular on the presentation and management of bladder, bowel and sexual dysfunction in CES, but also included a section on other relevant issues including pain and sensory problems, seeking subspecialist advice regarding content.

Links to the websites of relevant medical and paramedical societies and organisations are being developed in order to disseminate the information using the WWW. We have also included a feedback section, and will make changes and improvements as comments are received.

Results:

The website can be viewed at www.caudaequina.com and through UroHealth, a urology information website.

Conclusions:

Cauda equina syndrome is a disabling condition that generally affects patients who were previously healthy. We believe that many patients with CES are keen to have easily understandable, yet detailed information about their condition. From discussion with CES patients, it appears that many physicians and other healthcare professionals would also benefit from such information, in addition to a medically-oriented literature review on CES. We hope that patients will get some assistance from this website, particularly in learning to cope with their problems. Equally, we hope that it will be informative to all health professionals who have patients suffering from CES. Given the need for multidisciplinary management of CES, we believe that the WWW is a useful tool for disseminating information.