Spinal Cord (2001) 39, 584–588

www.nature.com/sc

Original Article

Community-care waiting list for persons with spinal cord injury

S Vaidyanathan*,[1], BM Soni[1], P Mansour[2], CA Glass[1], G Singh[1], J Bingley[1], JWH Watt[1] and P Sett[1]

[1]*Spinal Injuries Unit, District General Hospital, Southport, Merseyside, UK;* [2]*Department of Cellular Pathology, District General Hospital, Southport, Merseyside PR8 6PN, UK*

Objectives: To disseminate the concept of community care waiting lists for spinal cord injury (SCI) patients with particular reference to carer support for management of neuropathic bladder by a regime of intermittent catheterisation.
Methodology: The surgical waiting list focuses only on operative procedures, and ignores the wider requirements for ensuring satisfactory rehabilitation of people with spinal cord injury in the community. A community-care waiting list for individuals with spinal cord injury should include the following aspects of community care: (1) Home adaptation; (2) Provision of appropriate mobility needs (including wheelchair and cushion); (3) Equipment for comfortable living (including provision of hoist, pressure relieving mattress); (4) Psychological support for spinal cord injury patients and their partners; (5) Nursing home or residential care placement where appropriate; (6) Carer support for global management of complex needs associated with spinal cord injury (eg neuropathic bladder and bowel).
Results: Whereas full physical adaptation of the home can wait for some time after discharge, carer support for intermittent catheterisation is required from the first day after discharge from a spinal unit. Lack of such support means that some SCI patients are discharged with long-term indwelling urinary catheters, even though clean intermittent catheterisation is known to be the safest regime for managing the neuropathic bladder. Therefore, the absence of a community care waiting list means that best practice cannot be achieved for some tetraplegic subjects.
Conclusion: We believe that a community care waiting list for bladder management will help to provide optimum care for neuropathic bladder and, hopefully, reduce the complications related to long-term indwelling catheters in spinal cord injury patients.
Spinal Cord (2001) **39**, 584–588

Keywords: community care; waiting list, spinal cord injury; urinary catheters; urinary tract complications; intermittent catheterisation

Introduction

Young and Turnock,[1] in a recent issue of the *British Medical Journal*, produced a succinct and thought provoking article concerning the development of community care waiting lists for older people. The concept of generating a waiting list to address the global needs of disabled people could also be extended to those with spinal cord injury.

The community-care waiting list is essentially different from the conventional surgical waiting list, which provides only a simple summary statistic widely used in hospitals in the UK. This is not directly relevant to many individuals with spinal cord injury as the needs of SCI patients go beyond the traditional focus of the surgical waiting list. The surgical list focuses only on operative procedures, and ignores the wider requirements for ensuring satisfactory rehabilitation of people with spinal cord injury in the community. In contrast to the surgical waiting list, the community-care waiting list lays emphasis on preventive aspects of medicine for physical and mental well being. Consequently, the community-care waiting list, in our opinion, is preferable to the surgical waiting list, and should be adopted universally in spinal injury centres for resource allocation. We discuss how we are compelled to make compromises in bladder management, particularly in tetraplegic subjects, due to lack of a community care waiting list

*Correspondence: S Vaidyanathan, Regional Spinal Injuries Centre, District General Hospital, Town Lane, Southport, Merseyside PR8 6PN, UK

for support for carers learning to perform intermittent catheterisation.

Principal considerations in developing a community-care waiting list for people with spinal cord injury

A community-care waiting list for individuals with spinal cord injury should include the following aspects of community care:

(1) Home adaptation depending on the individual needs of spinal cord injury patients.
(2) Provision of appropriate mobility needs (including wheelchair and cushion).
(3) Equipment for comfortable living (including provision of hoist, pressure relieving mattress, kitchen aids, equipment for interaction with the environment for independent living such as use of telephones, computers, television, and so on).
(4) Facility for meaningful occupation and employment (including accessible Day care centres).
(5) Psychological support in the community for spinal cord injury patients and their partners.
(6) Nursing home or residential care placement (when home placement is not appropriate for a person with SCI).
(7) Support of walking aids (eg reciprocal gait orthosis).
(8) Carer training and support for global management of complex needs associated with spinal cord injury (including neuropathic bladder and bowels).

This list is not exhaustive and would need modification or addition in the light of prevailing clinical needs.

Supporting evidence

The process of home adaptation and provision of an appropriate wheelchair with cushion, for example, have been streamlined to a great extent in the UK. However, whilst people with spinal cord injury might now be reassured that they will eventually obtain such aids, significant waiting lists remain in many areas for both assessment and supply of these supportive measures, often entailing a considerable waiting period which extends long after their transfer from a spinal unit. Whilst waiting lists for the community equipment and environmental needs of those with spinal cord injury might easily be compiled, consideration of on-going clinical needs has been essentially ignored. Whereas full home adaptation and equipment for comfortable living may be provided after a waiting period, carer support for bladder management is required from the first day after discharge from a spinal unit. The following example highlights the danger of this omission.

To the best of our knowledge, a waiting list is not maintained for provision of carer support for bladder management for a person with spinal cord injury in the community. This necessitates a compromise in the urological care of some individuals, particularly those with cervical spinal cord injury. Although clean intermittent catheterisation has been identified as the safest bladder management method for those with spinal cord injury, in terms of having the lowest potential for urological complications,[2] the practice is not universally applied, even when clinicians consider this would be in the best interest of their patient. This is primarily because facilities for teaching and performing intermittent catheterisation in the community cannot be guaranteed. Therefore, some SCI patients are discharged from a spinal unit with long-term indwelling urinary catheters, thereby risking complications such as catheter-induced hypospadias (Figure 1) or vesical calculus (Figure 2A,B). These people who suffer from an essentially preventable disease are then put on a surgical waiting list, for removal of bladder stones or repair of catheter-induced hypospadias, for example. If a community care waiting list had been available, at least a sizeable proportion of these people could have been managed by intermittent catheterisation and the need for long-term urinary catheters would have been averted in many individuals with tetraplegia.

We cite an example of a fatal complication of long-term catheter drainage in a spinal cord injury patient. A 42-year old female with tetraplegia presented with haematuria. She had been managing her bladder with an indwelling urethral catheter for nearly 25 years. Cystoscopy revealed an inoperable bladder tumour, shown on biopsy to be a grade 3 squamous carcinoma (Figure 3). She died from bladder cancer 6 months later. Of course, vesical malignancy is an extreme example of the complications of long-term indwelling

Figure 1 Clinical photograph of the penis showing catheter-induced hypospadias: The urethra is split due to continuous traction by a long-term indwelling urethral catheter. This 70-year old man developed paraplegia (L-3) as a result of a gunshot wound while serving with the Royal Marines in 1945. His urea was 30.5 mmol/L and creatinine 900 umol/L

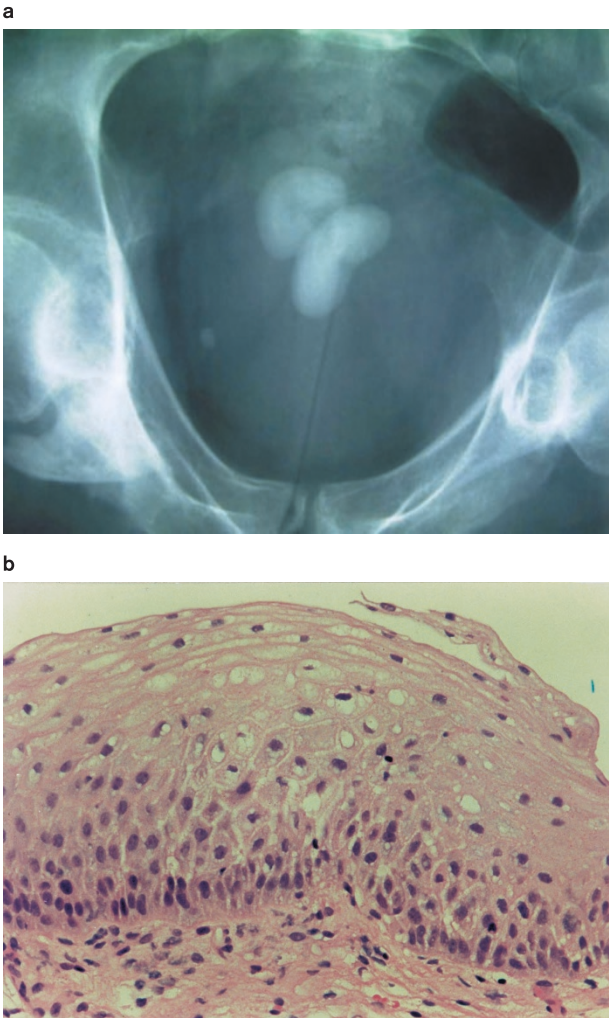

Figure 2 (A) X-ray pelvis in a 39-year old paraplegic patient, shows large bladder stones. (B) Bladder biopsy (H-4752/99) in the same patient as in A shows non-keratinising squamous metaplasia

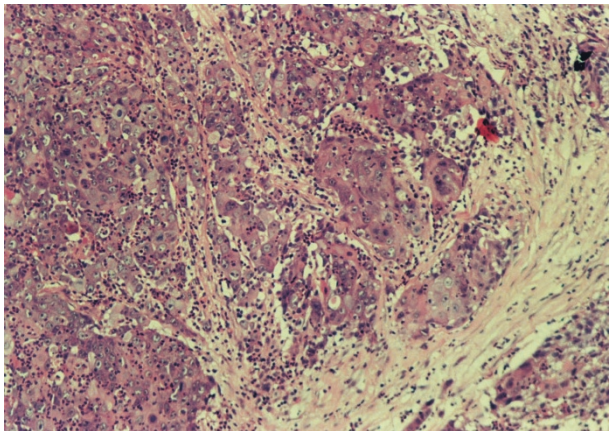

Figure 3 Biopsy (H-2536/99) shows a poorly differentiated squamous carcinoma grade 3 in a 42-year old female tetraplegic patient who had an indwelling urethral catheter for nearly 25 years

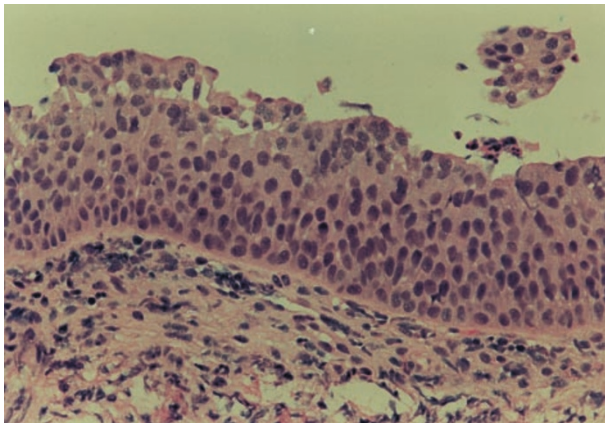

Figure 4 Bladder biopsy (HP00/03143) in a 30-year old tetraplegic patient who sustained C4/C5 dislocation as a result of diving in shallow water 3 years ago. He has been managing his bladder by an indwelling urethral catheter. The urothelium shows mild nuclear enlargement and hyperchromasia amounting to mild dysplasia falling short of carcinoma *in situ*

catheters in people with spinal cord injury, urinary infection and orchitis[3] being seen much more frequently.

Indwelling urinary catheters may induce potentially serious, but clinically imperceptible, changes in the bladder mucosa even within 5 years of sustaining spinal cord injury, as illustrated by the following case. A young man with tetraplegia was discharged home with a long-term indwelling catheter 3 years ago. He developed recurrent bladder stones, and bladder biopsy revealed extensive squamous metaplasia, the urothelium showing dysplasia falling short of carcinoma *in situ* (Figure 4). Wall and associates[4] performed immunohistochemical studies on mucosal biopsies obtained from 37 adults with spinal cord injury, all of whom had required a chronic indwelling urethral or suprapubic catheter for longer than 8 years. Inducible nitric oxide synthase was detected in inflammatory cells (identified immunohistochemically as macrophages), localised to the lamina propria. The enzyme was not detected in cadaveric organ donor specimens. The expression of inducible nitric oxide synthase in these circumstances may potentially lead to the sustained production of nitric oxide and its oxidative products, the nitrosation of urinary amines, and the formation of potentially carcinogenic nitrosamines in the bladder. This might explain the increased incidence of squamous cell carcinoma in the urinary bladder of spinal cord injury patients with long-term catheter drainage.[5]

Management of community care waiting list

If establishing community care waiting lists is to have relevance to ongoing clinical care, attention must also be paid to how, and by whom, community care might be provided. Simply recognising the inadequacies in care outlined in the previous section is insufficient. The staff of Regional Spinal Injuries Centres should take a lead role in addressing the following issues:

(1) Developing community care waiting list for spinal cord injury patients.
(2) Co-ordinating the allocation of resources for implementing the community care waiting list.
(3) Monitoring the delivery of effective care in the community to individuals with SCI.
(4) Imparting training to carers.
(5) Providing 24 h nursing and medical advice to (i) SCI patients and their carers, (ii) district nurses, and (iii) medical professionals in the community and in other hospitals, as SCI patients often require specialised nursing and medical attention.

Function of Regional Spinal Injuries Centres

A high quality service can be provided to spinal cord injury patients when the individual with SCI, his/her carers, General Practitioners, community nurses, social services and the staff of regional spinal injury centres are willing to work together to achieve a common goal. The aim is to provide global rehabilitation of excellent quality to SCI patients in the community. A close liaison between the 'community' and the 'spinal injury centre' staff will be the most important single factor for the success of community care waiting lists, as it is for the provision of continued care for SCI patients.[6] Thus, the Regional Spinal Injuries Units will be taking an enhanced profile during the twenty-first century. Of course, as in the past, the specialist staff of spinal units will offer their services to SCI patients during the period immediately after spinal cord trauma, but in addition to this established role, the staff of Regional Spinal Injuries Centres will place emphasis on the following new responsibilities:

(1) To act as a resource base for knowledge and expertise in spinal cord medicine, nursing, and rehabilitation at a more global level.
(2) To provide guidance and advice on medical and nursing care of SCI patients to the community health professionals on a 24-h basis.
(3) To offer 24-h open-door policy[7] for individuals with spinal cord injury.
(4) To develop innovative diagnostic methods and treatment strategies in spinal cord medicine.

Examples of this approach are: (1) trials to establish the efficacy and safety of nitric oxide donors (such as glyceryl trinitrate or isosorbide mononitrate) in delivering nitric oxide locally to the urethral sphincter muscle in men with detrusor-sphincter dyssynergia (DSD), so as to achieve short- or long-term lowering of urethral pressure;[8] and (2) standardisation of immunostaining patterns using cytokeratin 20 in urothelium of bladder biopsies obtained from patients with spinal cord injury, both to facilitate the diagnosis of mild urothelial dysplasia in the neuropathies bladder and to confirm the diagnosis of papillary cystitis in SCI patients by ruling out the possibility of grade 1 transitional cell carcinoma.

The Regional Spinal Injuries Centres should be able to function satisfactorily in the above-mentioned key areas of patient care, and SCI patients and community health professionals will feel confident that they can depend upon the spinal units for life-long care of persons with spinal cord injury. The community nursing and medical staff will then refer SCI patients to the spinal units for expert treatment, be it an emergency admission or a planned stay for an elective medical intervention.

Conclusion

Repeated catheter blocks and associated autonomic dysreflexia,[9] catheter-induced hypospadias, vesical calculus, urothelial dysplasia and urothelial malignancy, are avoidable complications of long-term indwelling catheters in spinal cord injury patients. We believe that a community-care waiting list for bladder management will help to provide optimum care for satisfactory management of neuropathic bladder and, hopefully, reduce the number of urinary tract complications related to long-term indwelling catheters in spinal cord injury patients.

Acknowledgement

We thank Coloplast Ltd, Peterborough, Cambs PE2 6FX, England for sponsoring the printing of colour illustrations in this article.

References

1 Young J, Turnock S. Community care waiting lists and older people. *BMJ* 2001; **322:** 254.
2 Vaidyanathan S *et al*. Lower urinary trace complications in spinal cord injury patients. *Urology News* 2001; **5:** 12–16.
3 Vaidyanathan S *et al*. Xanthogranulomatous funiculitis and epididymo-orchitis in a tetraplegic patient. *Spinal Cord* 2000; **38:** 769–770.
4 Wall BM *et al*. Inducible nitric oxide synthase in the bladder of spinal cord injured patients with a chronic indwelling urinary catheter. *J Urol* 2001; **165:** 1457–1461.

5 El-Masri WS, Fellows G. Bladder cancer after spinal cord injury. *Paraplegia* 1981; **19:** 265–270.
6 Krishnan KR, Vaidyanathan S, Soni BM, Watt JWH. Urine leakage from the umbilicus in a child with achondroplasia and tetraplegia (due to cervical stenosis): a safety vent for the obstructed neuropathic bladder. *International Urology and Nephrology* 1997; **29:** 45–51.
7 Vaidyanathan S *et al*. A review of the readmission of patients with tetraplegia to the Regional Spinal Injuries Centre, Southport, United Kingdom, between January 1994 and December 1995. *Spinal Cord* 1998; **36:** 838–846.
8 Mamas MA, Reynard JM, Brading AF. Augmentation of nitric oxide to treat detrusor-external sphincter dyssynergia in spinal cord injury. *Lancet* 2001; **357:** 1964–1967.
9 Vaidyanathan S *et al*. Pathophysiology of autonomic dysreflexia: long-term treatment with terazosin in adult and paediatric spinal cord injury patients manifesting recurrent dysreflexic episodes. *Spinal Cord* 1998; **36:** 761–770.