The management of neurogenic bladder and quality of life in spinal cord injury

Ja Hyeon Ku
Department of Urology, Seoul Veterans Hospital, Seoul, Korea
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INTRODUCTION
As healthcare has improved, life-expectancy after spinal cord injury (SCI) has increased; living with disability becomes a life-long process for many injured persons, with a different set of problems presenting themselves at different stages in life. Extended life spans and the need for a life-long follow-up make it important to expand the variables of medical care used to assess the outcome, to better understand and promote physical, psychological and social well-being after SCI. Thus, advances in medical and rehabilitative care have increased interest in their effect on the quality of life (QoL) of individuals with SCI.

QoL is partly a reflection of the individual’s ability to cope and adapt to his or her new life situation. For the QoL of persons with SCI, although the physical and practical restrictions due to the impairment are evident, personal roles and social activities can often be maintained. It is now recognized that a patient’s psychosocial adjustment to illness is as important as the status of the physical disease itself. Measures of QoL provide a meaningful way to document individual progress and response to treatment, beyond the limited traditional measures of mortality and morbidity. However, much remains to be discovered about the health of people with SCI in terms of functional health and well-being, the relative burden of disease, and the relative benefits of alternative treatments.

The management of neurogenic bladder (NB) dysfunction is a crucial component of a rehabilitation programme for SCI, because it continues to affect the morbidity of these patients [1]. Of patients with SCI in a study by the Model Spinal Cord Injury Systems of Care, 81% report some degree of impaired bladder function at 1 year after injury [2]. The loss of normal bladder function in patients with SCI is disabling and results in a greater risk of urinary tract deterioration, giving rise to significant morbidity and occasionally to mortality [3]. Lundqvist et al. [4] found that urinary incontinence reduced self-reported QoL among individuals with SCI. Similarly, Westgren and Levi [5] found lower QoL to be associated with NB problems.

The principal goals of managing NB are to preserve renal function and to maintain patient QoL by decreasing urological complications. With a proper bladder management method that optimizes both renal function and social functioning, the person with SCI can enjoy a much healthier life. Various approaches to managing urinary disorders have been developed in recent years, and different therapies have become available, ranging from surgery to the ingestion of active drugs, as well as the use of clean intermittent catheterization (CIC) or the insertion of endourethral prosthetic devices. I review the findings from several studies, which evaluated the impact of NB management on QoL in patients with SCI (Table 1) [6–23].

TREATMENT OPTIONS
Treatment options for NB can be divided into two groups: therapy to facilitate bladder filling or storage of urine, and therapy to facilitate bladder emptying. For facilitating storage, treatment options include surgical procedures such as electrical stimulation or interruption of innervation, intravesical therapies such as resiniferatoxin, capsaicin and botulinum toxin type A (BTX-A), and antimuscarinic drug treatment. Treatment options for facilitating voiding include catheterization or surgical procedures such as sphincterotomy, urethral stents and neurostimulation.

THERAPY TO FACILITATE BLADDER EMPTYING
CIC
In the 1970s, Lapides et al. [24] first promoted long-term CIC, and since then CIC has gradually gained acceptance. It has become the standard procedure for managing the NB of patients with SCI [25,26]. Individuals with adequate hand function using CIC are able to empty the bladder regularly, with a lower UTI rate and good continence between catheterizations. Recently, Weld et al. [27,28] presented CIC as the safest and most appropriate method of bladder management for these patients. This procedure has many beneficial effects, which include reduced morbidity and mortality, improved body image, and guaranteed improved self-esteem for the patient [27]. Vaidyanathan et al. [14] assessed QoL in patients with SCI before and during CIC, with adjunctive intravesical oxybutynin therapy. These patients achieved socially acceptable continence, with improved QoL and enhanced sexuality with the CIC regimen and intravesical oxybutynin therapy.

However, CIC is not a procedure to be undertaken lightly, and requires education and support, particularly during the initial stages, and during the follow-up [29]. Wyndaele [30] suggested that the most important preventative measures were a good education in all factors involved in CIC, good patient compliance, the use of proper materials and the application of a good catheterization technique. It is also important, after having given all the proper instructions, to follow-up patients regularly, to monitor their technique and to discuss any problems. Yavuzer et al. [31] found that of patients on CIC at discharge, 52% discontinued this method and reverted to an indwelling catheter during the follow-up. CIC is in many ways a disturbing procedure, and some patients experience the procedure as a form of trauma. Clinical experience suggests that especially females find this procedure
## TABLE 1 A summary of studies of QoL in patients with SCI

<table>
<thead>
<tr>
<th>Ref</th>
<th>Study design</th>
<th>N patients</th>
<th>Mean (range), age, years</th>
<th>Gender %</th>
<th>Time since injury</th>
<th>Level of injury: %</th>
<th>Neurological status: %</th>
<th>QoL measures</th>
</tr>
</thead>
<tbody>
<tr>
<td>[6]</td>
<td>Retrospective</td>
<td>79</td>
<td>41.9 (20–74)</td>
<td>M: 100</td>
<td>8.2 (1–14) years</td>
<td>NA</td>
<td>Com: 77</td>
<td>Tetra: 48</td>
</tr>
<tr>
<td>[9]</td>
<td>Retrospective</td>
<td>82</td>
<td>NA</td>
<td>NA</td>
<td>4.8 (0.1–25) years</td>
<td>NA</td>
<td>NA</td>
<td></td>
</tr>
<tr>
<td>[10]</td>
<td>Case series</td>
<td>3</td>
<td>32.7 (32–33)</td>
<td>F: 100</td>
<td>9.3 (5–15) years</td>
<td>C: 100</td>
<td>NA</td>
<td>VAS</td>
</tr>
<tr>
<td>[13]</td>
<td>Retrospective</td>
<td>77</td>
<td>11–40: 60%</td>
<td>M: 85 F: 16</td>
<td>7.6 ± 5.8 years</td>
<td>C: 47 T or L: 37</td>
<td>NA</td>
<td>NA</td>
</tr>
<tr>
<td>[14]</td>
<td>Case series</td>
<td>7</td>
<td>44.3</td>
<td>M: 100</td>
<td>NA</td>
<td>C: 14 T: 86</td>
<td>NA</td>
<td>NA</td>
</tr>
<tr>
<td>[15]</td>
<td>Prospective, MC, R, Lo</td>
<td>57</td>
<td>ES: 34.5 ± 9.9 SS: 39.1 ± 11.8</td>
<td>M: 100</td>
<td>ES: 8.7 SS: 6.6</td>
<td>C: 70 T: 30</td>
<td>NA</td>
<td>NA</td>
</tr>
<tr>
<td>[16]</td>
<td>Prospective</td>
<td>22</td>
<td>46.3 ± 11.9 (26–64)</td>
<td>M: 100</td>
<td>2.7 (0.5–18) years</td>
<td>C: 73 T: 27</td>
<td>NA</td>
<td>NA</td>
</tr>
<tr>
<td>[17]</td>
<td>Retrospective</td>
<td>21</td>
<td>34.6 (17–51)</td>
<td>M: 57 F: 43</td>
<td>NA</td>
<td>C: 100</td>
<td>NA</td>
<td>NA</td>
</tr>
<tr>
<td>[18]</td>
<td>Prospective, MC, R PC</td>
<td>178</td>
<td>NA</td>
<td>NA</td>
<td>NA</td>
<td>Com: 55 Incom: 46</td>
<td>Para: 51 Tetra: 17</td>
<td>Urinary Symptom QoL, IPSS QoL</td>
</tr>
<tr>
<td>[20]</td>
<td>Case series</td>
<td>6</td>
<td>17.8 (12–22)</td>
<td>M: 100</td>
<td>12.2 ± 10.6 years</td>
<td>C: 100 T: 53 L: 6</td>
<td>NA</td>
<td>NA</td>
</tr>
<tr>
<td>[21]</td>
<td>Retrospective</td>
<td>230</td>
<td>44.6 ± 14.2</td>
<td>M: 75 F: 25</td>
<td>NA</td>
<td>C: 37 L: 6</td>
<td>NA</td>
<td>NA</td>
</tr>
<tr>
<td>[22]</td>
<td>Prospective, MC, DB, R PC</td>
<td>59†</td>
<td>41 (20–72)</td>
<td>M: 61 F: 49</td>
<td>NA</td>
<td>NA</td>
<td>NA</td>
<td>Incontinence QoL</td>
</tr>
</tbody>
</table>

PB, population-based; Lo, longitudinal; MC, multicentre; R, randomized; DB, double-blind; PC, placebo-controlled; M, male; F, female; NA, not available; Q, questionnaire; VAS, visual analogue scale; GH, General Health; SAI, State Anxiety Inventory; CIC Pain and Discomfort; NHP, Nottingham Health Profile; KPI, Karnofsky Performance Index; ABS, Affect Balance Scale; Com, complete; Incom, incomplete; Para, paraplegia; Tetra, tetraplegia; O, others; C, cervical; T, thoracic; L, lumbar; S, sacral; ES, external sphincterotomy; SS, sphincteric stent; *irradiation cystitis in three patients. †Multiple sclerosis in six patients.
more distressing and uncomfortable than do males.

On the basis of a nationwide catheter-delivery programme, Bakke et al. [7] evaluated personal experiences and attitudes towards CIC in patients with SCI. Although most of the patients considered CIC an advantage, about a third had periodical or permanent aversion to CIC. Aversive reactions were associated with higher psychological distress. Dissatisfaction with and aversive reactions to CIC were reported by more women than men. Bakke et al. [7] also evaluated social function and well-being by the General Health Questionnaire-28 item version, State Anxiety Inventory and the CIC Pain and Discomfort Self-rating Scale. The most striking findings were the rather low to moderate scores in the group as a whole on all measures of social role function, health perceptions and well-being. They found a significantly higher frequency of unpleasant health perceptions, physical discomfort and state-anxiety among females than males, despite similarities in overall morbidity.

Oh et al. [23] examined the psychological and social status of Korean patients using CIC because of NB secondary to SCI. Health-related QoL (HRQoL) was measured using the Medical Outcomes Study 36-Item Short-Form General Health Survey (SF-36). The SF-36 scores showed no significant differences between the men and women in the patient group. The SF-36 scores of the patients were significantly lower than those of the general population. These findings suggest that patients with SCI experience physical and emotional difficulties in their daily lives, even when emptying problems are properly managed. Brillhart [21] also showed no significant difference in QoL and life satisfaction as a function of the type of urinary management system. These results showed that HRQoL might be altered in patients with SCI because of the presence of NB itself. However, the net effect on HRQoL from the use of CIC is highly likely to be generally better than that of other therapeutic strategies. Additional research is needed to resolve this continuing controversy, as most studies have not measured the effect of CIC against other treatments for such patients.

PENILE PROSTHESES

The value of penile implants in patients with NB has been reported. They permit external condom drainage and so maintain continence, prevent skin maceration in a small retractile penis needing glue and other sticking material to retain condoms, and vaginal penetration for sexual satisfaction. They have also been reported to be useful to facilitate CIC by lengthening and straightening the penis [32].

Perkash et al. [6] presented their analysis of 79 patients with SCI and a small retractile penis, who had an implant because the penis would not support a condom catheter. A patient-satisfaction survey showed a markedly increased self-esteem, increased mobility without fear of condom loss, and an improved sex life, although the long-term prosthesis failure rate was 8%. Kimoto and Iwatsubo [9] also reported similar results. Although extrusion and infection were significant problems, a penile prosthesis significantly improved QoL.

A treatment success rate of almost 85% in men with SCI and erectile dysfunction is comparable to results reported in men with no paralysis [33–37]. However, significantly many complications were reported in patients with SCI. Late erosion, extrusion or removal of the prosthesis was the result in 10–25% of such men [38–41]. Because of the high risk of complications and the many other possibilities available to obtain an erection in men with SCI, some authors do not currently recommend this kind of surgery for the sole purpose of erection [42].

EXTERNAL SPHINCTEROTOMY AND SPHINCTERIC STENT PROSTHESES

The rate of urological complications is ≥50% in patients in whom external detrusor-sphincter dyssynergia (EDSD) is associated with elevated maximum detrusor pressure. Complications include sepsis, hydronephrosis, VUR, nephrolithiasis, renal insufficiency and even renal failure. Current treatment options for EDSD, which serve to minimize intravesical pressure and its detrimental effect on the upper urinary tract, include oral spasmolytic medications, chronic indwelling or CIC, external sphincterotomy, and injection with BTX-A. Recently, innovative procedures such as balloon dilatation of the external sphincter, intraurethral stenting, and sacral posterior root rhizotomy with ventral root stimulation, have also been tried.

Kuo [13] reported the results of active urological management including external sphincterotomy (in 30 patients). The QoL for ‘urination’ after active urological management was better than that with no active management. Chancellor et al. [15] compared the treatment results of conventional external sphincterotomy with those of a sphincteric stent prosthesis in men with SCI and EDSD: 80–90% of the patients who had a sphincterotomy or stent reported that bladder emptying was ‘somewhat’ to ‘much better’ after surgery, and only 14% in each group had ‘some’ to ‘a lot’ of bothersomeness with urination.

PUDEINAL NERVE BLOCK

Phenol has been widely used as a neurolytic agent for the relief of spasticity. A pudendal nerve block using phenol solution is an alternative treatment for urethral sphincter hypertonicity. Because pudendal neurolysis can be done relatively non-invasively, it is easy on an outpatient basis.

Tsai et al. [16] studied the effects of pudendal nerve block with phenol on DSD in patients with SCI, and the QoL Index was assessed in all patients to evaluate satisfaction with and importance of urination. The mean QoL Index score increased from −0.74 before to 0.42 after treatment (mean increase, 1.16) with a statistically significant improvement.

THERAPY TO FACILITATE BLADDER STORAGE

AUGMENTATION CYSTOPLASTY

For a contracted bladder or intractable detrusor hyper-reflexia, the small bladder capacity and high intravesical pressure lead to severe frequency, urinary incontinence and upper tract deterioration. Augmentation cystoplasty is well-established surgery for treating these conditions.

Kuo [12] analysed 21 patients with augmentation enterocystoplasty and found that all but one declared that the QoL improved after surgery. Subsequently, Kuo [13] reported the results of active urological management including enterocystoplasty (in 28 patients). The QoL for urination after active urological management was better than that without.
CONTINENT URINARY DIVERSION

While patients with paraplegia and good hand function can self-catheterize with no difficulty, most patients with cervical SCI and upper extremity dysfunction depend on caregivers to perform the necessary catheterizations. In addition, women with quadriplegia face additional challenges secondary to the location of the female urethra and the difficulties involved in catheterizing with this degree of disability. For those quadriplegic women with detrusor hyper-reflexia that is unresponsive to medical therapy, management options include either cystectomy or enterocystoplasty, and the creation of either a continent or incontinent urinary stoma. A continent abdominal stoma is much more accessible and requires less dexterity than the native urethra, increasing the ease of catheterization.

Moreno et al. [10] presented the results of continent urinary diversion in three quadriplegic women who required cystectomy for end-stage NB complicated by urethral destruction as a result of chronic indwelling catheterization. The umbilicus was chosen as the urostomy site because of cosmetic appearance and ease of catheterization for a patient with minimal dexterity. After surgery, the incidence of symptomatic autonomic dysreflexia and UTI decreased, while body image and satisfaction with urological management increased. Of the two women who were sexually active, the frequency of activity increased and sexual enjoyment was improved. Kuo [13] reported the results of active urological management including continent urinary diversion (in seven patients). The QoL for urination after active urological management was better than that without. Zommick et al. [17] reported their experience with a selected group of patients with limited upper extremity function. Of these patients, 68% reported improved QoL since reconstruction, citing such reasons as a lack of need for urinary drainage bags, increased freedom, independence, dry between catheterizations and an improved sense of body image. Using a visual analogue scale to grade satisfaction from 1 to 10, 67% reported a score of ≥8. Walsh et al. [20] evaluated the results of a continent catheterizable stoma in females with cervical SCI. All patients reported a significant improvement in continence, body image, independence, convenience, time-saving and satisfaction. All the patients reported an improved QoL and were satisfied with the procedure, despite three requiring stomal revision for skin stenosis. They all agreed that they would undergo the procedure again, and recommend it to a friend.

INTRAMUSCULAR INJECTIONS WITH BTX-A INTO THE DETRUSOR

BTX-A blocks neuromuscular activity in skeletal muscle by preventing peripheral neurotransmitter release at presynaptic cholinergic nerve terminals. BTX-A might inhibit acetylcholine-mediated detrusor contraction and potentially inhibit other vesical-bound neurotransmitters in the afferent and efferent pathways of the bladder wall, urothelium or lamina propria.

Schuch et al. [22] determined the efficacy of BTX-A injected into the detrusor for urinary incontinence caused by neurogenic detrusor overactivity of predominantly spinal cord origin. There were significant decreases in incontinence episodes from baseline. Positive treatment effects were also reflected by significant improvements in bladder function in the BTX-A groups, as assessed by urodynamics and in patient QoL.

THERAPY TO FACILITATE BLADDER EMPTYING AND STORAGE

SACRAL RHIZOTOMIES AND ELECTRICAL BLADDER STIMULATION

In 1976, a new treatment, sacral posterior rhizotomy (SPR) and sacral anterior root stimulation (SARS), was introduced by Brindley et al. [43]. This combined technique of SPR and SARS of the bladder improves emptying of the bladder and achieves continence. In a study by Kutzenberger et al. [44], 464 patients received SPR and SARS; continence was achieved in 83%, autonomic dysreflexia disappeared in most, UTIs declined, and renal function was stable. Consequently, the satisfaction of patients was very high and they improved in independence and HRQoL.

Wielink et al. [11] studied the impact of SPR and electrical bladder stimulation on QoL in patients with SCI. General indicators of QoL showed no significant changes after the implantation. However, factors related to psychological well-being and the patients’ satisfaction with emptying of the bladder increased significantly, whereas the problems of micturition and incontinence all decreased significantly. That emptying of the bladder is just one of the many problems of patients with SCI might explain these smaller effects on QoL. Vastenholt et al. [19] assessed long-term effects and QoL of using SARS in patients with SCI. The Qualiveen questionnaire was used and the outcome was compared with data obtained from a reference group of 400 patients with SCI and NB problems not using the bladder controller. From users’ experiences, the most important advantages reported were a lower infection rate (68%), improved social life (54%) and continence (54%).

The results of the Qualiveen questionnaire indicated that with the bladder controller, the specific impact of urinary disorders on QoL aspects was reduced, and the overall QoL improved.

α-ADRENOCEPTOR ANTAGONISTS

Conservative treatment with pharmacological manipulations and/or CIC is the first-line option for managing a NB. Although anticholinergic drugs are widely used to treat detrusor hyper-reflexia and decreased bladder compliance, α₁-adrenoceptor antagonists also have a role in the treatment of NB [45]. In theory, α₁-adrenoceptor antagonists potentially have a role in facilitating both bladder storage and emptying, because of the following actions: reduction of detrusor hyper-reflexia thereby improving bladder filling and reducing storage symptoms, and a reduction of detrusor-bladder neck or possibly EDSD, leading to a reduction in voiding pressures and residual urine volumes [46].

Recently, Abrams et al. [18] evaluated the results of tamsulosin in patients with NB secondary to suprasacral SCI in a 4-week randomized controlled trial followed by a 1-year, open-label, long-term study. There was a statistically significant improvement in the IPSS QoL subscale, as well as several questions about symptoms related to urinary leakage, and one question on bladder emptying.

LIMITATIONS OF QoL MEASUREMENTS IN SCI

The purpose of a QoL instrument is to provide quantified assessments which are amenable to constructing a scoring index and to...
statistical analysis. Although QoL has been defined as different things to different people at different times in their lives, generally it refers to the physical, social, psychological, and existential aspects of well-being that might be affected by disease, disability and its treatments [47]. However, many issues remain unanswered, particularly when QoL assessments are applied to populations with physical disabilities.

The concept of QoL was assessed by a single-item measure or overall ratings on visual analogue scales in some studies [10,14,17,20]. However, no information on the psychometric properties of the measure was given. When overall ratings are used, QoL becomes unidimensional and undefined. No further information on specific areas makes the result hard to interpret and the value is questionable when used alone. In some studies, study-specific questionnaires were used to assess QoL [6,11,15,17]. These specific instruments were created for a specific purpose in a single study. However, the interpretation of results is questionable due to the unknown psychometric quality of the applied instruments. Another method of assessing QoL is the generic multi-item instrument [7,8,11,13,16,21,23], which measures general aspects of physical and/or mental health, functioning and well-being, and which enhance standardized methods when assessing QoL. However, a disadvantage to the exclusive use of generic measures is that condition-specific areas of life are not sufficiently covered and ‘floor and ceiling’ effects might be more common in patients with SCI than among the general population. Thus, although the reliability and validity of the generic instruments used were stated, there was not always evidence that they were tested on a population with SCI. Some studies assessed QoL by using disease-specific questionnaires [18,22], but these questionnaires were not developed to assess all types of urinary disorder in a way that is specific to populations with SCI. Furthermore, QoL was assessed only by an interview in some studies [9,12].

Measuring QoL is difficult in patients with SCI, as there are few disease-specific instruments available for this purpose alone, and most existing questionnaires are not appropriate in SCI. Therefore, because of the limited rigour of research design and poor validity of measurements, conclusions about the ability of rehabilitative care to improve QoL for people with SCI might not be drawn from the studies reviewed.

CONCLUSIONS

QoL is partly a reflection of the individual’s ability to cope and adapt to his or her new life situation. The effect of physical disability or illness cannot be understood without considering both the specific areas of functioning affected by the patient’s physical conditions and those aspects of QoL that are of particular importance to the individual [48]. Addressing QoL issues in the population with SCI is imperative, as most survive their initial injury and their longevity now approaches that of the general population.

As NB remains the most important issue in QoL of patients with chronic SCI, apart from physical movement, a more aggressive attitude to urinary management after SCI is needed to improve QoL. Before deciding the management plan for NB in patients with SCI, factors such as the type of voiding dysfunction, level of injury, the patient’s ability to use CIC, dressing and transfers, should be considered. The ideal treatment will be one which is least invasive, and which causes no permanent alteration in the patient’s body system. However, all these variables are not static, and are likely to change from time to time.

The reports of interventions generally show improved QoL after surgical procedures to improve bladder function. However, the results of most studies can be considered preliminary; most were cross-sectional with limited study populations. The cross-sectional study design precludes any conclusions about causation. Furthermore, the most important reason for this has been the lack of practical measurement tools appropriate for widespread use across this population.

Generic QoL questionnaires are too broad to evaluate changes that these patients notice in their lower urinary tract management. Questionnaires that have been developed for stress incontinence and overactive bladder in the able-bodied population have not primarily assessed the population with SCI. The Qualiveen questionnaire was developed to measure disease-specific aspects of limitations, constraints, fears and feelings, and generic QoL aspects, suitable for use in patients with SCI and urinary disorders [49]. The Qualiveen questionnaire might be supportive in studies investigating effects of treatment of urological disorder in patients with SCI. However, it is questionable whether this questionnaire considered all aspects of QoL, and it is only available in French, which limits its value.

Although one purpose of assessing QoL is to evaluate the effects of treatment, QoL can be influenced by diverse factors such as family support, adjustment and coping, productivity, self-esteem, financial stability, education, and the physical and social environment [50]. These factors should also be evaluated in future studies to assess whether the management of NB might improve the QoL in this population. Potentially, identifying and characterizing factors related to QoL in the population with SCI might accelerate the development of preventive, diagnostic and therapeutic strategies for improving QoL in this population.

CONFLICT OF INTEREST

None declared.

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Correspondence: Ja Hyeon Ku, Department of Urology, Seoul Veterans Hospital, 6–2, Doonchon Dong, Kangdong Ku, Seoul 134–791, Korea.

e-mail: randyku@hanmail.net

Abbreviations: SCI, spinal cord injury; (HR)QoL, (health-related) quality of life; NB, neurogenic bladder; CIC, clean intermittent catheterization; BTX-A, botulinum toxin type A; SF-36, Medical Outcomes Study 36-Item Short-Form General Health Survey; (E)DSD, (external) detrusor-sphincter dyssynergia; SPR, sacral posterior rhizotomy; SARS, sacral anterior root stimulation.