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Support groups in rehabilitation

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The International Classification of Functioning, Disability and Health (ICF) framework of the World Health Organization aims to integrate medical and social models of disability. It recognises that health disorders occur on two levels: body functions and structures (previously described as 'impairments'), and activities and participation.¹ Most formal rehabilitation is geared towards the activity domain, i.e. at achieving the highest possible functional level. However, the removal of barriers to life participation is often not possible within formal rehabilitation. It is in this area that support groups play a very valuable role.

Benefits of groups

A disabling illness or an accident is frequently associated with physical barriers that may be encountered as well as with limitations in life participation, the impact of which significantly affects quality of life. These often include loss of employment, changes in the role of the family and relationships, and loss of friends. Membership of a support group affords the person, and often the family members, the opportunity to create new social networks and to grieve and adjust with the support of other people who have had similar experiences. Group membership provides emotional support, a sense of universality, and the instillation of hope.² In addition, the group is a learning environment that has great power to effect change, as members are able to see how other people handle problems and as a result gain clearer insight into their own attitudes, beliefs and behaviours. Yalom² terms this 'cognitive learning' and identifies it as the key benefit of the group. The support group is more than a social group, because members experience growth by working together to address problems.

Group structure

Groups may be closed, in which no new members are admitted, or open. Most support groups for people with disabilities are open, with new members joining and

others leaving on an ongoing basis. While closed groups allow for the development of strong bonds between members, there is usually a stable core group in an open group. The fluctuations in the group's composition and dynamics provide an opportunity for longer-standing members to review changes and for new learning.³ The process of welcoming new members to the group, and of helping them to address some of the problems they confront, is empowering to older group members. It enables them to feel that they are in a position to help others, have an important role to play and have unique expertise and experience. It is also usual for support groups to have members with a wide range of severity. For the more severely involved members, there is the hope of improvement. Group members often talk of the 'inspiration' provided by those who have progressed well. For the less severely involved members, there is often a sense of relief that 'things are not as bad as they could be', and the benefit to self-esteem afforded by being able to provide help.⁴

'My colleagues and I believe that joining a group is the most important thing that a stroke survivor can do for himself or herself'.

Some support groups have a treatment function as well as a support function. To view this as a 'cheaper' alternative to individual treatment is incorrect. The group, representing a microcosm of the real world, is a very powerful milieu for the learning and maintenance of new skills, and, indeed, for some disorders (e.g. behavioural problems after traumatic brain injury) group treatment is often more effective than individual.⁵

Some support groups fall under the umbrella of a larger organisation which disseminates information, lobbies for services, and co-ordinates research endeavours in the area (e.g. The Parkinson's Disease Association). Others function as small, independent groups (e.g. Stroke Aid in various centres; Headway and Brainstorm in Johannesburg). Groups may

be facilitated by a professional person, a group member, or both. However, most groups include information-sharing sessions on a regular basis and various professionals are asked to assist in this regard.

Support groups in South Africa

Unfortunately there is no national directory of support groups. Most of the national bodies (e.g. QuadSA, Motor Neurone Disease South Africa, Parkinson's Disease Association) have contact details for local support groups. Community newspapers and local libraries and clinics are often the best sources of information about groups. Many patients and families eventually gain information about the groups from these sources, wishing they had known about the group's existence earlier. Because of their wide diversity in structure and function, support groups are often viewed with scepticism by health care professionals, who may see them as irrelevant or ineffective. However, the group should not be seen as a last resort for the desperate, but as an integral and essential part of the rehabilitation continuum. In the words of Roger Ross, a person with aphasia: *'I have a sense that, after my stroke, I did not get better until I met with other people with the same problem. My colleagues and I believe that joining a group is the most important thing that a stroke survivor can do for himself or herself'*.⁶

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Pitfalls in the long-term bladder management after spinal cord injury

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We have fortunately come a long way since the days when spinal cord injury (SCI) was considered 'an ailment not to be treated'.¹ SCI is a life-changing experience that brings with it the risk of numerous medical complications. Urological complications are still some of the most dangerous of these and optimal urological management is imperative in order to ensure that our patients with SCI are able to enjoy a normal quality of life.

The bladder, internal and external sphincters function as a unit in the whole process of continence and bladder emptying. The internal sphincter is under involuntary control while the external sphincter is controlled voluntarily.²

There are 2 main types of bladder dysfunction after SCI:

- **Suprasacral spinal cord lesion (hyperreflexic bladder)** – these patient present with a spastic bladder and internal sphincter and they often have DSD detrusor sphincter dyssynergia) where there is a lack of co-ordination between the detrusor muscle and internal sphincter. This is usually caused by a C1-T11 SCI.
- **Conus medullaris and cauda equina lesions (acontractile bladder)** – these patients usually present with a flaccid bladder and internal sphincter or with a combination picture. This is usually caused by a SCI (T12-sacrum).³

Urological management of the patient post SCI

The aims of urological management of the SCI patient are to:

- prevent upper tract complications (e.g. hydronephrosis, renal failure)
- prevent lower tract complications (e.g. cystitis, bladder calculi)
- develop a programme where the patient is continent and where the patient will be able to re-integrate easily back into society.¹

The early urological management of patients post SCI, irrespective of the level of injury, is usually with an indwelling urethral catheter (size 12 - 14) which should

ideally be inserted in the trauma unit. Most patients continue with an indwelling urethral catheter for the first few weeks after an injury until they are medically stable enough to enter the rehabilitation phase of their treatment. The long-term management of the patient's bladder then depends on the level of injury of the patient and his/her type of bladder dysfunction. The gold standard for the management of both male and female, paraplegic and tetraplegic patients (with sufficient hand function) with both suprasacral and conus or cauda equina lesions is clean intermittent self-catheterisation (CISC). This is usually performed with a size 12 - 14 male or female, especially designed re-usable, catheter and is performed 4 - 6 hourly while fluid intake is initially limited to 1 500 ml/24 hours. Bladder volumes should not exceed 400 - 500 ml per time during initial training of catheterisation. CISC is performed using a clean but not sterile technique. It is however important to remember that many patients with suprasacral SCI will require anticholinergic medication to be added to treat detrusor hyperreflexia.³

SCI is a life-changing experience that brings with it the risk of numerous medical complications.

In many tetraplegic patients (male and female) who require indwelling catheters suprapubic catheters are a good long-term alternative. Indwelling catheters (urethral and suprapubic) should be changed every 8 - 12 weeks and a fluid intake of 2.5 - 3 litres per day should be maintained in order to minimise the risk of complications.

In some men with SCI condom sheath drainage of their bladder is an option with a distal sphincterotomy to abolish dyssynergia.³

In certain patients with detrusor hyperreflexia, where anticholinergic treatment has failed, surgical methods are necessary for bladder management. During augmentation cystoplasty the bladder is bisected and augmented with a patch of bowel. The aim of this is to provide a compliant bladder that can accommodate a good volume of urine. CISC usually needs to be performed after this procedure. In patients who battle

to access their urethra for CISC, a self-catheterising stoma (Mitrofanoff) can be done as part of this surgery. In patients with complete suprasacral cord lesions complete emptying can sometimes be achieved by the stimulation of the anterior nerve roots of S2, S3 and S4 by means of an implanted neurostimulator. However, cost is a limiting factor in the use of these stimulators.³ Some very interesting studies are also currently being performed on the use of botulinum toxin (Botox, Dysport) in the urological treatment of patients with detrusor hyperreflexia. Botulinum toxin is however not yet registered in South Africa for this purpose.

Complications of voiding dysfunction after SCI

Urinary tract infections

Studies by Lloyd and Associates showed that in a group of 181 patients discharged from a centre treating patients with acute SCIs with sterile urine and on various forms of bladder management, 66.7 - 100% had at least one episode of urinary tract infection (UTI) in the first year post injury.¹ Bacteriuria is therefore a very common problem in patients after SCI. Signs and symptoms of a UTI include: dysuria, frequency, urinary incontinence, haematuria and increased abdominal or lower extremity spasticity. There is however consensus that patients managed with indwelling catheters with asymptomatic bacteriuria should not be treated with antibiotics as this can increase the incidence of resistant organisms. Patients with symptomatic UTIs can be started on a course of empiric antibiotics while awaiting the culture, which can then be adjusted as required. Treatment usually lasts for 7 days.¹ It is however important to have a good idea of the type of organisms in your unit as well as their sensitivity to enable one to make an educated decision regarding the choice of your initial antibiotic. Patients with high fevers should always be considered to have possible upper tract involvement (e.g. pyelonephritis) and treatment should then be continued until the fever has resolved. Possible further investigations into the cause of the urosepsis (e.g. IVP) should however be done in these cases. The role of long-term prophylactic antibiotics is still controversial but the general consensus is that prophylactic agents do not in the long term significantly reduce the risk of UTIs when compared with controls.¹

Hydronephrosis

Patients with poor bladder compliance, detrusor sphincter dyssynergia or outlet

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obstruction can develop a functional obstruction due to raised intravesical pressures. Ureteral dilation occurs when ureteral peristalsis cannot overcome these raised pressures. In the long run this leads to further ureteral dilatation and hydronephrosis. Other causes of ureteral dilatation include *Citrobacter sp.* and *Escherichia coli*.¹

Vesicoureteral reflux

Studies have shown that this is one of the factors that plays a role in long-term bladder deterioration post SCI. Patients with voiding dysfunction often have high intravesical pressures which, together with recurrent cystitis, appear to be major causes of reflux.¹

Renal calculi

Around 8% of patients will develop renal calculi after SCI, and there is a high incidence of renal deterioration in these patients. Patients who present with *Proteus* and other urea-splitting organisms also have a high risk of calculi formation. These patients have to not only be treated but also followed up very well as calculi have a high risk of occurrence.¹

Patients with SCI have been found to have a higher incidence of bladder cancer.

Renal failure

In the 1960s this was the leading cause of death of patients with SCI. Improved urological follow-up and management have significantly decreased this risk. The important causes of bladder deterioration include vesicoureteral reflux, renal calculi and recurrent pyelonephritis.¹

Bladder cancer

Patients with SCI have been found to have a higher incidence of bladder cancer. Causes include chronic irritation from urinary tract infections, stasis of urine and bladder calculi. Indwelling catheters are also a major risk factor in the development of squamous cell bladder carcinoma and all patients with indwelling catheters should have yearly cystoscopy.¹

Patients with SCI have complex pathology affecting many systems of the body and need to be treated by a whole team of

professionals on a continuous basis to ensure optimal quality of life after their injury. Special care needs to be taken that these patients are especially carefully followed up from a urological point of view in order to prevent the catastrophic results of long-term urological complications.

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Bowel management after spinal cord injury

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The neurogenic bowel seldom causes life-threatening problems, but is notorious for the profound effect it has on the quality of life of individuals disabled by spinal cord injury (SCI). The primary functional loss is the loss of *voluntary* control over defaecation. There are two types of neurogenic bowel. In the upper motor neuron or reflex bowel, the anal sphincter remains tight and bowel movement will occur on a reflex basis. This type of bowel is best managed by *reflex emptying*, after suppositories or digital stimulation. In the lower motor neuron or flaccid bowel, the anal sphincter tone is relaxed. The flaccid bowel is usually managed by manual evacuation, requiring laxatives, but may be able to empty using abdominal muscles.

What is a bowel programme?

This is a programme that should provide predictable and complete (i.e. no socially embarrassing leaks) elimination and reduce evacuation problems and gastrointestinal complaints. A bowel programme usually requires regular revision within the established parameters of safety and effectiveness. The design should take into account a patient's functional ability, availability of a caregiver/attendant, personal goals, life schedules, role obligations of the individual and self-rated quality of life. It is usually initiated during acute care and while it changes regularly, is continued through life.

Consistency of stool, type of rectal stimulant and frequency of emptying usually differ in reflex and flaccid bowels.

Establishing a bowel programme

The first step is to ensure that the patient is taking adequate fluid, is active and on a balanced fibre-rich diet (at least 30 g per day). Then choose an appropriate rectal stimulant and method to provide rectal stimulation to trigger defaecation. Select optimal scheduling and physical positioning as well as the assistive technique. Evaluate medication that promotes or inhibits bowel function. For example, a laxative could be taken 3 times per week on the night before, in the morning a rectal suppository is inserted followed by a waiting period of approximately 15 - 20 minutes, preferably on the commode or toilet seat. Programmes vary, are usually required between 3 and 4 times per week to avoid colonic distention and take about 30 - 60 minutes each time; they therefore have to be tailored to individual needs and schedules.

A combination of the following is usually used, again individualised to each patient's needs. Increasing stool volumes with regular oral fibre supplementation, together with oral laxatives such as senna preparations given the night before combined with either manual removal, a mini-enema or in well-trained/experienced patients a colonic lavage (such as Coloplast) are key ingredients of an effective flaccid bowel management programme.

Rectal suppositories such as Bisacodyl (which increases sigmoid peristalsis) or glycerine (which draws fluid into the stools) followed 10 - 50 minutes later by digital stimulation, which is circular motion with the index finger in the rectum, or with finger extensions or digital stimulators, may result in effective emptying in a reflex bowel.

Push-ups, abdominal massage, Valsalva manoeuvre and deep breathing are some of the adaptive techniques which augment complete emptying of the bowel. A colostomy or ileostomy may be considered when all attempts at bowel management have failed.

What could go wrong?

- **Accidents.** If this happens often, it may be necessary to re-evaluate the management schedule. It could be due to inadequate emptying during the bowel programme and the method needs to be reviewed. If it is happening consistently after certain foods, these should be avoided.

- **Diarrhoea** occurs when there is a frequent passage of more than 3 loose watery stools in 24 hours. If the diet is the cause, remove offending food or fluid. Check factors such as alcohol consumption, stool softeners and fibre intake. Rule out impaction. Note any fever as this may be due to a medical illness. Medication, especially antibiotics, may cause diarrhoea – consider adding yoghurt or probiotics.
- **Stool too soft** – add more fibre, at least 30 g per day. Add constipating foods to diet such as cheese, meat and starches.
- **Constipation** – unusually long bowel care periods with small results and dry hard stools. Establish a balanced diet with added fibre of at least 30 g per day. Increase fluid intake to 2 - 3 litre/day and if possible increase physical activity. Review any medication, e.g. anticholinergics, antacids, antidepressants and analgesics that could be the cause.
- **Impaction** – this is the collection of hardened faeces in the lower intestine and should be suspected when there has been no bowel movement for 3 - 5 days. It is probably the most common complication in SCI and can usually be seen on an abdominal X-ray. If the impaction is situated high in the bowel give oral medication and a suppository, e.g. Bisacodyl. If this is unsuccessful then give a mini-enema followed by manual removal. Leakage of a watery stool around impaction

may often be interpreted as diarrhoea; an X-ray is the best way to differentiate leakage in an impacted bowel from diarrhoea. A regular bowel plan must then be established every 2 days with an increase in fibre intake. Fluid and lactulose syrup may be added to soften the impaction. If the person is prone to develop autonomic dysreflexia, use topical gel with 2% lidocaine while trying to evacuate the bowel and monitor the blood pressure if there are any signs of sweating, headache, flushed cheeks, etc.

- **Rectal bleeding** – the most common cause of rectal bleeding in SCI is traumatic superficial mucosal erosion, which manifests as bright red streaks usually on the glove or stool and is usually due to trauma and haemorrhoids, manifesting as blood dripping into the commode or passing of clots. A rectal examination and proctoscopy should be done. This is associated with chronic constipation and may be treated medically; if there is no response, surgical intervention is required. Colorectal cancer should be ruled out in individuals over 45 years who have a positive faecal occult blood test or a change in bowel function that does not respond to corrective intervention.
- **Autonomic dysreflexia** occurs in patients with injuries above T6. Faecal impaction is the most common cause

of autonomic dysreflexia in SCI. Less common causes are massive abdominal distention and digital stimulation. Topical gel containing 2% lidocaine applied rectally can help to prevent this and could be given 1 hour before attempting to clear impaction in persons with SCI known to be prone to dysreflexia. They may complain of distorted vision, goose bumps, sweating above the level of the lesion, feeling flushed and having a blocked nose. Bradycardia and high blood pressure are usually present.

Conclusion

It is evident that in the life of a person with an SCI the bowel has the upper hand and steers life's daily way. Sadly, the importance of 'the bowel' is often grossly neglected and underestimated. It is important to remember that a person with SCI can still present with all the diseases of a person without SCI, but now has the added burden of the complications that may develop due to SCI.

Further reading

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Single suture

Marathons reduce overall death rate

Contrary to popular perceptions, the risk of sudden death while running a marathon is in fact very low – only 0.8 per 100 000 participants – or 26 observed deaths in 14 million hours of exercise. This according to Donald A Redelmeier and Ari Greenwald, writing in the *British Medical Journal* in December. Their study encompassed results for more than 3 million runners on 750 separate days, all competing in organised, well-established marathons. And not only is the rate of sudden death among runners low, but marathons actually reduce the overall death rate in an area by reducing the number of fatalities in motor vehicle accidents that would have happened had the roads not been closed to traffic for the duration of the event.

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