Rehabilitation outcomes in persons with Spina Bifida, Royal Melbourne Hospital

Spina bifida (SB) encompasses a range of congenital neural tube defects, with an annual incidence of 1 per 1000 live births worldwide (7 per 10,000 live births in Australia).\(^1\) SB related impairments (such as neuromuscular weakness, neurogenic bladder or bowel, hydrocephalus, cognitive impairment, bone or joint deformity, insensate skin etc.) can cause limitation in ‘activity’ (reduced mobility, self-care ability, cognitive dysfunction) and ‘participation’ (employment, study, family and social reintegration) (4, 7).\(^2,3\) As disease progresses other issues surface, such as degenerative musculoskeletal issues, cardiopulmonary disease, obesity, bowel and bladder issues, latex sensitivity and others.\(^2,4\) These disabilities can have a cumulative effect in this patient population, reduce their quality of life (QoL) and can cause considerable distress. Persons with SB require concurrent rehabilitation for longer-term management in conjunction with medical and surgical management.\(^5,6\) Rehabilitation provides medically supervised patient-centred interdisciplinary (ID) care delivered by various health disciplines that maximise activity and participation.

A randomised controlled trial (RCT) was conducted to assess the effectiveness of a structured ID rehabilitation program to improve disability and participation in an adult SB population in the Royal Melbourne Hospital (RMH), a tertiary referral centre in Victoria, Australia. The RMH has the only state-wide ID clinic in Victoria to address the many disabilities faced by young adults with SB as they transition from paediatric to adult services. They are referred from public and private clinics across the state and enrolled in the SB transitional clinic database held at the RMH in conjunction with the Department of Health, Victoria. A total of 54 adult patients with SB were randomized to a treatment group (n=27) for high intensity rehabilitation program (with cognitive-behaviour therapy), or a control group (n=27) comprising usual care. The ID rehabilitation program included 30 minute blocks of individual therapy sessions, 2-3 times per week for 6 weeks. These comprised a physical reconditioning program, wheelchair and seating evaluation, task reacquisition skills and whole body adaptive techniques. Participants in the treatment group, in addition to the ambulatory rehabilitation program, received individualised ID care with intensive focus on education for self-management, continence and skin care, and a cognitive-behaviour program for an additional 4-6 weeks beyond the usual program. Within the ID rehabilitation program, continence care included: an individualised bladder management program and structured bowel program: fibre-supplements (manufactured and marketed locally, such as “NutriKaneTM”), where necessary, laxatives and anal irrigation as appropriate provided by nursing and medical staff for faecal continence. Participants’ assessments were at baseline (T1 before intervention), at 3-months post-intervention (T2) using validated questionnaires.

Participants were predominantly female (57%), average age 33 years. With bowel and bladder dysfunction reported by one-third of all participants. As a part of the structured bowel management program, all participants in the treatment group were provided with additional fibre supplement (“NutriKaneTM”). At 3-months post-treatment follow-up (T2), both bowel and bladder function improved significantly in the intervention group compared with the control group, with moderate to large magnitude in outcome measures. The treatment group compared with the control group, also showed a significant reduction in psychological distress, and improved QoL at 3-months follow-up. At 3-months follow-up, just over half
(55%) participants reported continued use of the fibre supplement (NutriKane™). The reported reason behind this discontinuation included: consistency, taste, hard to swallow and difficulty in preparation. The participants also suggested that they will continue to take fibre supplement (NutriKane™) in future, if the product quality (taste, consistency) improved. None of the participants reported any adverse effects related to the program or fibre supplement. The findings suggest that a comprehensive, coordinated clinical approach targeting specific symptoms (such as bowel/ bladder symptoms) and cognitive-behaviour strategies for self-management, coping and psychological adjustment; improve symptoms, psychological problems and enhance overall quality of life of persons with SB.

References