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Effectiveness of the Interdisciplinary Ambulatory Rehabilitation Program in Persons with Spina Bifida

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Abstract

This randomised controlled trial assessed the effectiveness of an interdisciplinary (ID) ambulatory rehabilitation program for persons with Spina Bifida (pwSB) in an Australian community cohort. Fifty-four participants were randomized to a treatment group for high intensity ID rehabilitation program (with cognitive-behaviour therapy), or a control group comprising usual care (n=27 participants in each group). Assessments were conducted at baseline, and 3-months post-intervention, using validated outcome measures. The findings suggest that, participants in the intervention group at 3-months, significantly improved for primary and secondary outcomes: urinary/bowel dysfunction, cognitive functions, and quality of life. Targeted rehabilitation can improve clinical outcomes in pwSB. Further research is needed for longer-term outcomes related to 'aging' and participation restriction.

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Introduction

Spina bifida (SB), is a congenital neural tube defect with unknown etiology [1]. With advances in medical care and better management of disease-related complications, the survival of persons with SB (pwSB) has improved (78% survive to >17 years) however, many have disease and age-related secondary disabilities, which require interdisciplinary (ID) care over a lifetime [2-4]. It remains a significant cause of chronic disability worldwide and is associated with financial, economic and personal costs to the pwSB, their careers and the community [4].

Spina bifida related impairments (such as neuromuscular weakness, neurogenic bladder or bowel, hydrocephalus, cognitive impairment, bone or joint deformity, insensate skin) can cause limitation in 'activity' (reduced mobility, self-care ability, cognitive dysfunction) and 'participation' (employment, study, social reintegration) [5,6]. Numerous complications result from various childhood procedures (such as ventriculo-peritoneal shunts, urinary diversionary procedures, orthopaedic surgery), and as disease progresses other issues surface, such as tethered cord, syringomyelia, degenerative musculoskeletal issues, osteoporosis, cardiopulmonary disease, obesity, latex sensitivity and others [2,5,6]. These disabilities have a cumulative effect in pwSB, which reduce their quality of life (QoL) and can cause considerable distress. They require concurrent rehabilitation for longer-term management in conjunction with medical and surgical management [1,7]. Previous reports suggest that SB population is found to be physically inactive and 26-61% have some form of mobility restrictions [8,9]. There is evidence that exercise training improves aerobic and strength training and cardiorespiratory endurance [9]. Further, though majority of pwSB have normal intelligence, many have specific cognitive disabilities, which are amenable to cognitive remediation [1,10].

Although several studies in the paediatric population demonstrate effectiveness of a coordinated ID approach to management, this does not extend to adults and there is lack of comprehensive ambulatory care models [11-13]. The aim of this study, therefore, was to assess the effectiveness of a structured ID rehabilitation intervention to improve disability and participation in an adult SB population in an Australian community cohort.

Method

Participants and Setting

The study was conducted at the Royal Melbourne hospital (RMH), a tertiary referral centre in Victoria, Australia, with the only state-wide ID clinic in Victoria to address the disability management for pwSB. Participants Inclusion criteria was: >18 years; confirmed diagnosis of SB (clinical and radiological), able to communicate and understand English, and ability for informed consent. Exclusion criteria included: medically unstable or with unstable psychiatric disorders limiting participation in rehabilitation, bed-bound and/or institutionalized, inpatients at RMH during the study period and those who received inpatient care in the 6 months preceding recruitment.

Procedure

All eligible patients (n=85) were invited to participate in this project (HREC number 2012.078) by an independent project officer and those who fulfilled aforementioned inclusion criteria and provided written consent were recruited. An independent statistician randomized participants either to the treatment or control groups using a computer-generated sequence, with allocation concealed from the treating team. Face-to-face assessments (approx 45-minutes) were conducted by two independent researchers at baseline (T1) and 3-months (T2) following completion of the ID rehabilitation program for the treatment group, and 3-months after initial assessment for the control group. The assessors (a physician and a research nurse) were not in contact with the treating team or shared information about participants or assessments.

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The assessors collected participant information using standardized instruments (see measures below).

Treatment schedules

The RMH centre-based program included 30 minute blocks of individual therapy sessions, 2-3 times per week for 6 weeks (provided by PT, OT and SW), such as physical reconditioning program, wheelchair/seating evaluation, task reacquisition skills and whole body adaptive techniques. Subsequently, participants were involved in similar maintenance programs either at home or in the community while not attending the treatment centre. Participants in the treatment group, in addition to the ambulatory rehabilitation program, received individualized ID care with intensive focus on education for self-management, continence and skin care, and a cognitive-behaviour therapy (CBT) program for an additional 4-6 weeks beyond the usual program. The study interventions followed the Template for Intervention Description and Replication (TIdieR) Check list [14] (Box 1).

The participants in the control group received a standard outpatient rehabilitation program (supervised by their family doctors) as per usual practice, at home or at a local community rehabilitation centre as appropriate. Compliance with the program was defined as participant attendance in >80% of the education/treatment sessions. Adverse effects of rehabilitation program were noted (injury during treatment, pain, fatigue, etc.).

Measurements

The ICF was used as a conceptual basis for choice of best outcomes for measurement and validated measures were used: Disability: Guy's Neurological Disability Scale (NDS) (assessed neurological disability); Urogenital Distress Inventory (UDI6) (assessed the degree to which the symptoms associated with urinary incontinence (UI)); American Urological Association Symptom Index (AUA) (assessed severity of urinary symptoms); Incontinence Impact Questionnaire (IIQ7) (assessed the impact of urinary and bowel incontinence on daily life); Wexner Faecal Incontinence Score (WFIS) (assessed bowel symptom severity); Participation: Depression Anxiety Stress Scale (DASS) (assessed the negative emotional states of depression, anxiety and stress); McGill Quality of Life questionnaire (MQOL) (assessed overall QoL); Brief Cope scale (B-COPE) (assessed effective and ineffective coping) and Generalized self-efficacy scale (GSE) (assessed a general sense of perceived self-efficacy) [15-24].

Statistical analysis

The primary outcome was the impact of intervention on disability (bladder/bowel). A sample of 22 participants in each group was needed for an 80% chance to detect a 3 point difference between the intervention and control groups in UDI6 and IIQ7 from baseline to 3 months, assuming a standard deviation of 3.5 in both groups [25]. Non-parametric tests (Mann-Whitney U tests) compared change scores (baseline minus 3 months post treatment) on each of the outcome measures for the control and treatment groups. Clinically important changes were estimated as effect sizes (ES, r) using Cohen's criteria (0.1=small, 0.3=medium, 0.5=large effect). The estimate was based on a two sided $\alpha=0.05$.

Results

Of the 85 eligible patients, 54 provided written consent to participate, were randomised and allocated to the treatment and control groups (27 participants in each). One participant in the treatment group and 3 participants in the control group dropped out at the 3-month follow-up. The compliance rate of the intervention group with their rehabilitation program was 82%. (Figure 1)

Baseline characteristics

Mean age of participants was 33.3 ± 9.3 years (range=18 to 49 years) and majority (57%) were female. Although baseline demographic and medical characteristics was similar across treatment arms, participants in the intervention group had more myelomeningoceles (18 vs. 13) and L3-L5 level of injury (16 vs. 10), compared with the control group; this however, was not statistically significant. Participants in both groups reported neurogenic bladder and bowel, and one-half had some degree of cognitive impairment. Bowel incontinence (and overflow) was reported by 29 participants, while severe constipation by nine participants. Majority reported urinary incontinence (65%); with commonest bladder pattern of detrusor hyporeflexia. Approximately 48% used urinary catheters for drainage. All used some aid for their mobility: such as orthopaedic bracing, crutches or wheelchair. No adverse events were reported in either group. There was no significant difference between participants lost to follow-up and those who provided post-treatment results in terms of demographic and medical characteristics (Table 1).
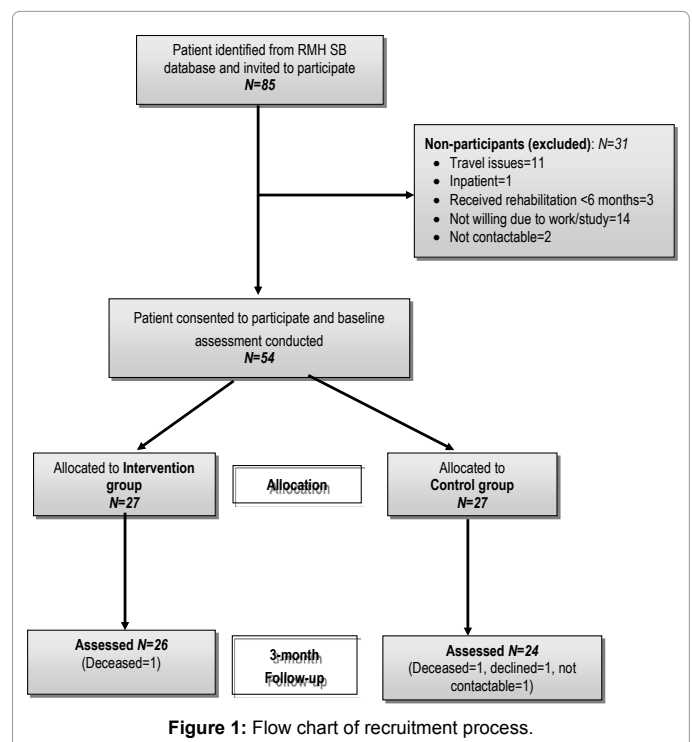
Figure 1: Flow chart of recruitment process.

• Individualised bladder management: assessment of bladder type, pattern and function, bladder re-education, behavior management, pelvic floor exercises, strategies for timed/double voiding, catheter care and medication review.

• Structured bowel program: fibre-supplements (such as "NutrikaneTM"), and where necessary, laxatives and anal irrigation.

• Skin and pressure care education sessions: pressure lifts, seating and equipment review.

• Cognitive behaviour therapy (CBT): 4-6 sessions over a 6-week period comprising 2-hour centre-based CBT sessions co-ordinated by a senior clinical psychologist (6 participants per sessions). This included coping strategies and self-management, and discussion topics selected by participants such as: self-esteem/stigma, help-seeking/assertiveness, relaxation, anxiety, depression/mood, goal setting/happiness (leading to valued life) and others.

Box 1: Components of the interdisciplinary rehabilitation program.

Characterisitics		Intervention group (n=27)	Control group (n=27)
		n, (%) (unless stated different)	
Age (years)	[Mean (SD), range]	32.9 (9.2), 18.4-47.5	29.7 (9.2), 18.5-48.8
Sex	Female	18 (66.7)	13 (48.1)
Married/Partner		3 (11.1)	4 (14.8)
Living with Partner/ Family		19 (70.4)	20 (74.1)
Tertiary education		17 (63.0)	8 (29.6)
Employed		11 (40.7)	14 (51.9)
Carer		14 (51.9)	13 (48.1)
SB type (n=46)			
Meningocoele		7 (28.0)	5 (23.8)
Myelomenningocoele		18 (72.0)	16 (76.2)
Level of Injury (n=44)			
≈ L2		5 (21.7)	3 (14.3)
L3-L5		16 (69.6)	10 (47.6)
<S1		1 (4.3)	7 (33.3)
VP stunt >1 (n=51)		15 (57.7)	17 (68.0)
Co-morbidities		17 (62.9)	9 (33.3)
Latex allergy		3 (11.1)	8 (29.6)
Symptoms			
Cognitive impairment		18 (66.7)	16 (59.3)
Contracture		9 (33.3)	11 (40.7)
Bladder dysfunction		22 (81.5)	20 (74.1)
Bowel dysfunction		23 (85.2)	19 (70.4)
Mobility (WC/crutches/braces)		17 (63.0)	11 (40.7)
At high risk of pressure area		12 (44.4)	12 (44.4)

n=Total Number; SB=Spina Bifida; SD=Standard Deviation; VP=Ventriculoperitoneal; WC=Wheel Chair
Table 1: Socio-demographic characteristics of participants (n=54).

Outcome measurements change scores

Change in subjective disability outcomes: At 3-months follow-up (T2), both bowel and bladder function improved significantly in the intervention group compared with the control group. There was a significant difference between treatment and control group participants in favour of the intervention group in IIQ-7, UDI, AUA and WFIS total scores, (p<0.001 for all), with moderate to large ES (r=0.4 to 0.7) and NDS 'bladder' and 'bowel' subscales (p<0.05, r=0.3 for both). Compared to their control group counter parts, significant improvement in cognitive symptoms was also seen in the intervention group (NDS 'cognitive disability' and 'mood' subscales: p<0.01, r=0.6 for both) (Table 2).

Change in participation and QoL outcomes: At 3-months follow-up (T2), compared to the control group participants, statistically significant improvement in the participants in the treatment group was seen in: DASS 'depression' (p<0.001, r=0.6), 'anxiety' (p<0.001, r=0.7) and 'stress' (p<0.001, r=0.5) subscales; MQOL total (p=0.013, r=0.5) and 'psychological symptoms' subscale (p<0.001, r=0.8); Brief COPE 'active coping' subscale (p=0.035, r=0.3) and GSE total score (p<0.001, r=0.5). Significant improvement in QoL in relation to current urinary symptoms, was also found in favour of the intervention group (single item AUA QoL scale, p=0.004, r=0.4). No difference between groups was noted in other subscales (Table 3).

Discussion

To our knowledge this is the first RCT evaluating effectiveness of an ambulatory ID rehabilitation program specifically designed to address symptomatology and psychological issues in pwSB residing in the Australian community. The findings demonstrate that a comprehensive, coordinated clinical approach targeting specific symptoms (such as continence), and cognitive-behaviour strategies (for self-management, coping and psychological adjustment), improve

Scales (score range)	Intervention group (n=26)	Control group (n=24)	Z Value	P Value	Effect size
	Median (IQR)	Median (IQR)			
AUA					
Total (0-35)	6.5 (0, 9.25)	0 (0, 0)	-3.81	**<0.001**	0.54
QoL (0-6)	0 (0, 1.0)	0 (-1.75, 0)	-2.84	**0.004**	0.40
IIQ-7 (0-21)	2.0 (0, 5.5)	0 (-1.75, 0)	-4.47	**<0.001**	0.63
UDI (6-24)	2.0 (0, 4.0)	0 (-1.0, 0)	-5.07	**<0.001**	0.72
WFIS (0-20)	0.5 (0, 3.25)	0 (-0.75, 0)	-4.34	**<0.001**	0.61
GUY's NDS (0-5)					
Cognitive disability	1.0 (0, 2)	0 (0, 0)	-3.95	**<0.001**	0.56
Mood	1 (0, 2)	0 (-0.75, 0)	-4.41	**<0.001**	0.62
Visual	0 (0, 0)	0 (0, 0)	-1.70	0.089	0.24
Speech	0 (0, 0)	0 (0, 0)	0.00	1.000	0.00
Swallowing	0 (0, 0)	0 (0, 0)	-0.06	0.951	0.01
Upper limb	0 (0, 0)	0 (0, 0)	-0.47	0.641	0.07
Lower limb	0 (0, 0)	0 (0, 0)	-1.20	0.229	0.17
Bladder	0 (0, 1)	0 (-0.75, 0)	-1.97	**0.049**	0.28
Bowel	0 (0, 1.5)	0 (0, 0)	-2.29	**0.022**	0.32
Sex	0 (0, 0.5)	0 (0, 0)	-0.52	0.604	0.07
Fatigue	0 (-0.5, 0.5)	0 (0, 0)	-0.52	0.605	0.07
Other	0 (0, 0)	0 (0, 0)	-0.31	0.758	0.04

Effect size was calculated as r=z/square root of N where N=total number of cases. Values above 0.5 represent large effect sizes.

AUA: American Urological Association Symptom Index; ES: Effect size; IIQ7: Incontinence Impact Questionnaire; IQR: inter quartile range; NDS: Guy's Neurological Disability Scale; n=total number; QoL: Quality of Life; UDI6: Urogenital Distress Inventory
Table 2: Summary of analysis of disability outcomes of interdisciplinary rehabilitation program.

Scales	Intervention group (n=26)	Control group (n=24)			
	Median (IQR)	Median (IQR)	Z Value	P Value	Effect size
DASS					
Total (0-126)	15.0 (2.0, 37.5)	-2.0 (11.5, 0)	-5.86	**<0.001**	0.83
Depression (0-42)	7.0 (1.5, 14)	0 (-11.5, 0)	-4.61	**<0.001**	0.65
Anxiety (0-42)	2.0 (0, 12.5)	-3.0 (-7.5, 0)	-4.72	**<0.001**	0.67
Stress (0-42)	3.0 (0, 12.5)	-2.0 (-4.0, 2.0)	-3.74	**<0.001**	0.53
MQOL					
Total (0-150)	-9.0 (-23.0, 1.0)	0.5 (-7.5, 11.3)	-2.49	**0.013**	0.35
Single item scale (0-10)	-0.5 (-2.0, 1.0)	0 (-1.0, 0)	-0.84	0.402	0.12
Physical symptom (0-30)	-3.0 (-6.25, 1.3)	0 (-4.0, 1.8)	-0.93	0.402	0.13
Physical wellbeing (0-10)	0 (-2.0, 2.0)	-2.0 (-3.8, 1.0)	-1.03	0.305	0.15
Psychological symptoms (0-30)	-5.5 (-12.3, -1.8)	3.0 (0.3, 5.8)	-5.92	**<0.001**	0.84
Existential wellbeing (0–60)	-2.0 (-5.3, 4.3)	-2.0 (-4.0, 1.8)	-0.16	0.876	0.02
Support (0-20)	-1.0 (-2.0, 0.3)	0 (-1.0, 0)	-0.69	0.492	0.10
B-COPE Total (28-112)	-3.0 (-13.5, 3.8)	3.5 (-4.5, 23.8)	-1.56	0.118	0.22
Problem-focused coping strategies (2-8)					
Active coping	-1.0 (-3.0, 0.3)	0 (-1.0, 2.0)	-2.11	**0.035**	0.30
Planning	0 (-3.0, 1.3)	0 (-2.5, 2.8)	-1.49	0.136	0.21
Positive reframing	0 (-2.3, 1.3)	0.5 (-1.0, 3.8)	-1.36	0.173	0.19
Acceptance	0.5 (-2.0, 4.0)	0.5 (-1.8, 3.5)	-0.08	0.938	0.01
Humour	0 (-1.0, 1.0)	0 (-0.8, 2.0)	-0.37	0.712	0.05
Religion	0 (-0.3, 1.3)	0 (0, 1.0)	-0.28	0.812	0.04
Using emotional support	-1.0 (-2.3, 0.3)	0 (-1.8, 2.0)	-1.76	0.079	0.25
Using instrumental support	-1.0 (-2.0, 1.3)	0.5 (-2.0, 3.0)	-1.00	0.319	0.14
Emotion–focused coping strategies (2-8)					
Self-distraction	-1.0 (-3.0, 0.3)	-1.0 (-3.0, 2.0)	-0.46	0.645	0.07
Denial	0 (0, 0)	0 (0, 0.8)	-0.52	0.605	0.07
Venting	0 (-0.3, 2.0)	0 (0, 2.0)	-0.93	0.353	0.13
Substance use	0 (0, 0)	0 (0, 0)	-0.29	0.773	0.04
Behavioural disengagement	0 (-0.3, 1.3)	0 (0, 0)	-0.71	0.480	0.10
Self-blame	0 (-1.3, 2.0)	0 (0, 1.8)	-0.36	0.717	0.05
GSE (10-40)	-1 (-9.3, 0)	0.5 (0, 3.0)	-3.50	**<0.001**	0.49

Effect size was calculated as r=z/square root of N where N=total number of cases. Values above 0.5 represent large effect sizes.
B-COPE: Brief Coping Scale; DASS: Depression Anxiety Stress Scale, ES: Effect size, GSE: Generalized Self-Efficacy Scale; IQR: inter quartile range; MQOL: McGill Quality of Life; n=total number

Table 3: Summary of analysis of participatory outcomes.

activity and participation in these patients. The treatment group showed a significant reduction in bladder and bowel related disability and psychological distress, and improved QoL (and psychosocial gains) at 3-month follow-up. Participants in this study were similar to those in other studies in terms of age, gender, disease severity and treatment [26-30].

Rehabilitative and supportive care needs are frequently experienced by pwSB many years after initial treatment [11,12]. In this study many participants reported ongoing transient and/or persistent physical and psychosocial morbidity such as bowel and/or urinary dysfunction and psychosocial issues, consistent with other reports [28,31,32]. Further, cognitive impairments are common, with detrimental effect on their emotional health and coping ability [33]. Similar to other cohorts, many participants (almost 50%) in this study were dependent on their carers for management and support [34]. The positive effects on various aspects of bladder/bowel and cognitive/behaviour function in this study are also reported in different SB subgroups and settings [3,4,13,14,35,36]. The improvements in bladder/bowel dysfunction, cognitive and other outcomes (QoL, coping strategies) were independent of study participants' demographic and clinical characteristics, which

suggest the need to further engage pwSB in rehabilitation activities. The study participants were complex in terms of disease severity, symptoms and co-morbidities (reflective of clinical practice), which required an individualized approach.

This study has some potential limitations, such as- small sample, selection bias, as participants were a selective cohort listed on a single database held at single tertiary institution (RMH) who agreed to participate in research projects, thus potentially limiting generalizability of the findings. However, the study cohort came from the only state-wide ID clinic, representing a wider sample of SB in the community. Comparison and generalizability of these results is difficult, larger sample sizes in different settings are needed to confirm these findings. We acknowledge that other factors may have impacted bowel/bladder and psychological issues in participants and were not studied. Although the vast majority of patients had incomplete spinal cord injury, there was no tool or measure to document this precisely. A generic pressure sore grading classification was used for risk management. To reduce potential bias the treating therapists and assessors were blinded. Important outcomes such as impact on carers and families and costs

associated with care, were beyond the scope of this study.

In conclusion, targeted ID rehabilitation care has much to offer pwSB throughout the disease continuum for maintaining activity and participation over the longer-term. This has implications for health service delivery, planning and policy. More research is needed for the effectiveness of 'specific' rehabilitation interventions in this population, cost efficacy and return to work/education; and longer-term outcomes related to aging with disability and contextual factors associated with participation restriction.

Acknowledgement

Ethical Approval

The study was approved by the Royal Melbourne Hospital Ethical Committee (No. 2010.216) and informed consent was obtained from all the participants.

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