Authors:

Brad E. Dicianno, MD
Melissa H. Bellin, PhD, MSW, LCSW
Andrew T. Zabel, PhD

Affiliations:

Human Engineering Research Laboratories (BED), University of Pittsburgh, Pittsburgh, Pennsylvania; Department of Physical Medicine and Rehabilitation (BED), Adult Spina Bifida Clinic, University of Pittsburgh, Pittsburgh, Pennsylvania; Department of Rehabilitation Science and Technology (BED), University of Pittsburgh, Pittsburgh, Pennsylvania; School of Medicine (BED), University of Pittsburgh, Pittsburgh, Pennsylvania; VA Pittsburgh HealthCare System (BED), Center of Excellence in Wheelchairs and Associated Rehabilitation Engineering, Pittsburgh, Pennsylvania; University of Maryland School of Social Work (MHB), Baltimore, Maryland; and Kennedy Krieger Institute (ATZ), Baltimore, Maryland.

Correspondence:

All correspondence and requests for reprints should be addressed to Brad E. Dicianno, MD, Suite 202 Kaufmann Building, 3471 Fifth Avenue, Pittsburgh, PA 15213.

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ORIGINAL RESEARCH ARTICLE

Spina Bifida and Mobility in the Transition Years

ABSTRACT

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Objective: Adolescents with spina bifida experience decreased mobility (Johnson KL, Dudgeon B, Kuehn C, et al: *Am J Public Health* 2007;97:330–6), especially during the time of transition from pediatric to adult care, but little research has been done on the relationships between mobility and self-management skills, psychological health, or quality of life.

Design: In this multicenter, interdisciplinary study, a convenience sample of 61 participants with spina bifida from regional spina bifida clinics (mean age = 21.0 ± 2.1 yrs) participated in a structured clinical interview on self-management and completed standardized self-report measures of psychological distress, quality of life, and mobility status. Participants were divided into three mobility groups: ambulators, part-time wheelchair users, and full-time wheelchair users and were compared with respect to outcome measures.

Results: We found that full-time wheelchair use is associated with reduced quality of life but that psychological distress and problems with self-management are prevalent, regardless of mobility status.

Conclusion: Research should be aimed at assessing life satisfaction as it relates to assistive technology use to delineate further how technological advancements in wheelchair design and universal design of homes and communities can have the greatest impact on mobility and quality of life.

Key Words: Mobility Limitation, Psychological Stress, Quality of Life, Rehabilitation, Self-Care, Spinal Dysraphism

The World Health Organization International Classification of Functioning, Disability, and Health[1] stresses mobility as being a crucial factor in participation and overall health and well-being. Mobility is important for individuals to maintain independence, perform activities of daily living, continue employment, participate in community and leisure activities, and maintain life satisfaction.[2] However, mobility impairments are common among individuals with spina bifida (SB), and many lead sedentary lives compared with those without disabilities.[3] Mobility is especially important during the transitional years, when individuals leave pediatric care as adolescents and become more independent. Obesity or weight gain, executive dysfunction, navigation through unfamiliar settings, such as college campuses, and insurance barriers to obtaining the equipment needed for mobility and adaptive exercise are a few examples of the obstacles to mobility-related health these individuals face during transition.[4] Clinicians prescribe assistive technology (AT), such as orthoses and wheelchairs, to attempt to improve physical mobility and function and to allow individuals to achieve personal life goals. Yet, little research has been done to document whether these interventions actually improve self-management, quality of life (QOL), or psychological health in this population or whether impairments in these domains exist despite mobility status.

A comprehensive review of the literature on adolescent and adult SB revealed that large research gaps exist on outcome measures such as mobility in SB.[5] In a subsequent study, Dicianno et al. showed that adults with SB who use manual and power wheelchairs had lower daily home and community activity levels compared with ambulators, despite being prescribed high-quality devices. This difference was significant even when statistically controlling for differences in motor level and history of hydrocephalus.[4] Although AT is a fundamental medical necessity in this population, some discrepancies in mobility status may still exist despite our best rehabilitative efforts. Environmental obstacles, accessibility issues, and social stigma related to device use may explain this gap in function.

Young adults may be at particularly high risk for impairments in other domains of functioning as a result of having limited mobility. This study was part of a larger, multicenter investigation of adaptation in transition-age individuals with SB.[5a] We hypothesized that, when compared with part-time wheelchair users and independent ambulators, individuals who use wheelchairs full time would have lower self-management skills, lower self-report of QOL, and increased levels of psychological distress.

METHODS

This study was approved by the respective Institutional Review Boards of the University of Pittsburgh Medical Center, Kennedy Krieger Institute, SUNY Upstate Medical University Hospital, Loyola University Medical Center, and Gillette Children's Specialty Hospital. The participants were recruited at these regional SB centers by postcard mailings and during medical visits. To ensure that the participants fully understood the study procedures, an Evaluation to Sign Consent Form adapted from the MacArthur Competence Assessment Tool[6] was administered by the study staff after each participant reviewed the combined informed consent document. To be enrolled in the study, the potential participant must have met or exceeded a commonly used cutoff score (8 of 10) on the Evaluation to Sign Consent form.

Inclusion criteria were clinical diagnosis of SB and age between 18 and 25 yrs. The participants underwent a structured clinical interview on self-management and completed a self-report background questionnaire. The questionnaire included general questions on demographics and medical history. They were also asked whether they ambulated in their homes or the community and what mobility and assistive devices or orthoses were used.

We collected the Hopkins Symptom Checklist-25.[7] A total score of 44 or higher is indicative of psychological distress. The participants who scored in the clinical range for distress were referred to local mental health services.

The Adolescent Self-Management and Independence Scale II, a structured clinical interview with established psychometric properties, was used as a measure of self-management skills.[8] Self-reported knowledge and behavior in 17 general activities of daily living, including transportation (taking initiative to arrange transportation and getting to the correct destination especially in unfamiliar settings), accessibility (safety, seeking accessible entrances, and being mobile in the environment), personal safety, knowledge of SB, medication management, money management, household skills, and community living skills were examined for each participant using this interview. Possible total scores ranged from 17 to 119, with higher scores indicating higher levels of independence. Descriptive categories for most items were as follows: independent with activity (7 points), modified independent (6), requiring supervision (5), and categories that required minimal (4), moderate (3), maximal (2), or total (1) assistance.

We also collected the World Health Organization Quality-of-Life Brief Instrument,[9] calculating a total score from 24 items spread across four factors (environment, physical health, psychologi-

TABLE 1 Device use according to mobility group

	Ambulators	Part-Time Wheelchair Users	Full-Time Wheelchair Users	Total	Percent
N	25	13	23	61	
Able to walk throughout home	25	10	0	35	57.4
Able to walk in community	23	7	0	30	49.2
Needs orthoses to walk	10	12	0	22	36.1
Needs assistive devices to walk	4	12	0	16	26.2
Manual wheelchair	0	13	23	36	59.0
Power wheelchair	0	1	6	7	11.5

Columns do not add up to total *N* because many subjects used more than one device.

cal, and social). Items were scored 1–5, yielding a possible range of 24–120 points.

Finally, a chart review provided additional medical history, including functional motor level, history of hydrocephalus, height, and weight. Arm span data were not collected.

The participants were divided into three mobility groups: ambulators who do not use wheelchairs, part-time wheelchair users, and full-time wheelchair users (FT). Significant levels were set at 0.05 a priori. The groups were compared with respect to age using analysis of variance; with respect to body mass index using Kruskal-Wallis; and with respect to gender, race, functional motor level (which was divided as thoracic, lumbar, and sacral according to the work of Hommeyer et al.[10]), insurance type, and history of hydrocephalus using χ^2 analysis or exact statistics. Motor level and hydrocephalus were the only two factors found to be significantly related to mobility status. Thus, three-way analyses of variance were then run to evaluate for differences in Adolescent Self-Management and Independence Scale II, World Health Organization Quality-of-Life Brief Instrument, and Hopkins Symptom Checklist-25 scores using mobility group, motor level, and the presence or absence of hydrocephalus as the fixed factors. Where significant interactions were found, Tukey's b was then used for post hoc analysis.

RESULTS

Sixty-one individuals with SB (mean age = 21.0 ± 2.1 yrs, 60.7% females) were recruited. Most participants had a primary diagnosis of myelomeningocele ($n = 51$, 81.6%). No participant was excluded based on competence assessment. Forty-seven participants (77.0%) were Caucasian, 8 (13.1%) African American, 3 (4.9%) Hispanic, and 3 (4.9%) mixed or missing race. Forty-two participants (68.9%) had a history of hydrocephalus. Nineteen participants (31.1%) were sacral level (intact S1, plantar flexion), 11 (18.0%) low lumbar (intact L4–5, knee flexion), 10 (16.4%) mid lumbar (intact L3, knee extension), 13 (21.3%) high lumbar (intact L1–2, hip flexion), and 8 (13.1%) thoracic (had no lower-limb strength). FT were more likely to have a history of hydrocephalus ($P = 0.007$) and higher motor level ($P < 0.0001$), but there were no other significant differences based on other baseline demographics, including body mass index. However, the average body mass index for all three groups fell into the overweight category.

Table 1 shows device use according to the mobility group. Thirty-six participants were manual wheelchair users, 23 of whom used a manual wheelchair full time, and 13 participants who used a manual wheelchair part time. There were six FT power wheelchair users, and one part-time power wheelchair user. All of the power wheelchair users reported that they also used an additional manual wheelchair. Table 1 also shows additional details regarding ambulation and use of assistive devices and orthoses.

Table 2 shows the average outcome measures per mobility group. There were no statistically significant differences in mean Hopkins Symptom Checklist-25 scores for the three mobility groups. The ambulators who did not use wheelchairs had the highest proportion of participants with scores above the clinical cutoff score for psychological distress ($n = 12$, 48.0%), followed by the FT group ($n = 8$, 34.8%) and the part-time wheelchair users group ($n = 2$, 15.4%).

The total self-management scores showed a trend across groups, with the average score of FT more than 20 points lower than the other groups, but these differences were not statistically significant in this sample.

Total World Health Organization Quality-of-Life Brief Instrument scores differed significantly among mobility groups, with FT having significantly lower scores than the other two groups ($P = 0.042$), even when we controlled for hydrocephalus and motor level. All subscale scores were similarly lower across groups; no individual subscale score

TABLE 2 Results of outcome measures by mobility group

	Ambulators	Part-Time Users	Full-Time Users	Total	Percent	*P*
N (%)	25 (41.0)	13 (21.3)	23 (37.7)	61	100.0	
No. female	16	9	12	37	60.7	0.546
No. patients with hydrocephalus	12	9	21	42	68.9	0.004
Body mass index, kg/m^2	26.3 ± 7.8	28.2 ± 7.4	28.3 ± 6.4			0.244
Mean age	21.2 ± 2.0	20.5 ± 2.5	21.2 ± 2.1			0.645
Mean total HSCL-25 score	42.5 ± 11.8	35.4 ± 8.1	43.8 ± 11.1			0.744
Mean AMIS II	89.2 ± 21.1	81.7 ± 25.2	63.0 ± 20.4			0.587
Mean total WHOQOL	101.0 ± 12.4	103.1 ± 10.4	92.0 ± 13.6			0.042

solely explained the differences seen among groups.

DISCUSSION

Because functional deficits are less likely in those with less severe neurological findings, it was important to control for confounders such as motor level and hydrocephalus. The significant relationship found between mobility status and both history of hydrocephalus and motor level is consistent with that of previous reported literature, as is the proportion of individuals using various types of AT.[4,11–14] Thus, the population studied here seems to be representative of the overall population of individuals with SB in this age group.

Our study of young adults with SB showed a high prevalence of psychological symptoms across all mobility groups, with higher percentages observed than those reported in typically developing standardization samples (Bellin MH, Zabel AT, Dicianno BE, et al, unpublished data, 2009). The underpinnings of this psychological finding are likely multifactorial, and it seems that independent ambulation does not reduce the risk of psychological distress in this population. Because independent ambulation in SB is often characterized by gait abnormalities and use of orthoses or assistive devices, it may be that physical accessibility issues or negative social regard impacts all individuals with SB regardless of whether they ambulate or use wheelchairs. We plan more in-depth research to identify the specific technology and accessibility issues faced by these young individuals with SB as well as the impact of social stigmas, but certainly, research should continue to aim at improving maneuverability, cosmesis, size, and transportability of wheelchairs and assistive devices.

Although psychological distress symptoms were not higher in the FT group, QOL was significantly lower in this group. This may suggest a dissociation of psychological distress and QOL in this clinical population. Bier et al. argue that maximizing functional independence is the key to improving health-related QOL.[15] Although neurological impairments from SB can certainly result in lower QOL, this study shows that full-time wheelchair use is an independently associated factor. Other physical health issues may be contributing to lower QOL, but another explanation is that either the wheelchair itself or the individual's experience in using the wheelchair may be a barrier to life satisfaction given the trend seen across groups. The questions of World Health Organization Quality-of-Life Brief Instrument assess the user's environment and social well-being, which could be limited by physical and social barriers presented by technology use in the community and which may be impacted more by the use of a wheelchair than the use of orthoses or assistive devices. Prior research has shown that many individuals perceive their own wheelchairs as barriers to life satisfaction either because of social stigma or because their device does not solve all accessibility obstacles, especially in the community.[16] Our results suggest that QOL may be a better measure of the impact of the physical environment on daily activities and participation rather than psychological symptoms or the measures of self-management used.

Prior research shows that functional independence varies greatly, depending on factors such as hydrocephalus or motor level.[17] Not all components of the Adolescent Self-Management and Independence Scale II directly assess physical mobility as it relates to each self- care task and may explain why no differences were found. Yet, our findings suggest that problems with self-management are common even in those young adults who continue to ambulate despite controlling for confounding neurological variables. Control data from young adults with no impairments do not exist for the Adolescent Self-Management and Independence Scale II and are a needed area of research. Psychological health issues that impact self-care activities may exist regardless of mobility status, and we plan more research into identifying the risk and protective factors associated with psychological functioning. Our study, however, shows that those using wheelchairs part and full time had self-management skills on par with ambulators, suggesting that their AT contributes at least in part to some self-management activities.

This study shows that full-time wheelchair use in transition-age individuals with SB is associated with reduced QOL but that psychological distress and problems with self-management are prevalent, regardless of mobility status. Research should be aimed at assessing life satisfaction as it relates to AT use to delineate further how technological advancements in wheelchair design and improvements in universal design of homes and communities can have the greatest impact on mobility and QOL.

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