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ORIGINAL RESEARCH ARTICLE

Mobility, Assistive Technology Use, and Social Integration Among Adults with Spina Bifida

ABSTRACT

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Objective: Many individuals with spina bifida have impairments that limit mobility and functional independence. Sedentary lifestyles and social isolation are very prevalent. This study evaluated the association between the use of mobility devices and degree of socialization.

Design: A retrospective chart review was performed on 208 adults with spina bifida attending a university-based clinic. Data collected included the Craig Handicap Assessment Reporting Technique-Short Form, Beck Depression Inventory, and data on wheelchair and other assistive technology use. We hypothesized that community and home mobility and social integration, as measured by the Craig Handicap Assessment Reporting Technique-Short Form, would be lower for manual and power wheelchair users than for ambulators, regardless of depression scores or shunt history.

Results: We found that individuals with spina bifida who used both manual and power wheelchairs do have lower daily home and community activity levels compared with ambulators, but that most individuals with spina bifida have low social integration and economic self-sufficiency scores, regardless of whether they can ambulate or use wheelchairs. These findings were not explained by wheelchair quality because most were prescribed high-quality devices. A high prevalence of depression was also found.

Conclusions: Special considerations for wheelchair provision are discussed. Additional research is needed to identify other barriers to social integration.

Key Words: Depression, Rehabilitation, Socialization, Spinal Dysraphism, Self-Help Devices, Walking, Wheelchairs

More than 70,000 Americans have a diagnosis of spina bifida (SB),[1] and many have impairments that limit mobility and functional independence. Although many individuals with SB use manual wheelchair (MWC) or power wheelchair (PWC) to assist with mobility and independence in the home and community, research[2,3] has suggested that sedentary lifestyles and social isolation are still very prevalent in the population with SB. A previous study[4] found that independent mobility was one of the most important determinants of health-related quality of life in SB. However, little is known about the use of mobility devices and other types of assistive technology (AT) in the adult population with SB and how such use might augment or impede socialization.

Preservation of mobility through rehabilitative measures improves physical function and functional independence, and in turn, health-related quality of life.[5,6] A previous study by Johnson et al.[7] retrospectively reviewed the charts of 348 adolescents with SB and reported that the use of AT is common in this population but that little is known about how well the technology needs of individuals with SB are met and what impact this may have on other domains of life, including social integration. The authors pointed out the need to assess satisfaction with AT and to identify which secondary complications may occur from inadequate technology. They also postulated that underutilization of AT might be a barrier to community participation and transition to adulthood and independent living. The study by Johnson et al. included retrospective data from as far back as 1960, which predated much of the mobility technology available today and limits external validity of the study. However, to our knowledge, that manuscript has been the only large study evaluating AT use in the population with SB. In a recent comprehensive review article on adult with SB,[8] we discussed the paucity of literature on how technology is related to mobility, activity, and participation. Barriers in access to adequate and appropriate technology may influence these outcomes.

Previous studies by Cate et al.[9] and Verhoef et al.[10] have shown that the cognitive consequences of hydrocephalus and shunting negatively impact mobility and social interaction. In addition, a need for more cognitive assistance in the community might correlate with mobility limitations in those with SB who use wheelchairs. Rendeli et al.[11] reported that nonambulatory individuals with SB, who often had near normal global intelligence quotient, were likely to have much lower nonverbal intelligence quotient scores and perceptual organization abilities than those with SB who ambulate. This suggests that wheelchair users may require more cognitive assistance in the community, which may impact their social integration.

Research has also shown a reciprocal relationship between community involvement and depression. Barnett and Gotlib[12] identified low social integration as a factor in the etiology of depression; depression, in turn, has been linked to reduced community integration.[13] Thus, studies on mobility and social integration must take into account the impact that depression may have on these outcomes.

The purpose of this study was to expand on the study by Johnson et al.[7] and evaluate the association between mobility status and the extent of social integration in adults with SB. We hypothesized that, overall, social integration and community and home mobility, as measured by the Craig Handicap Assessment Reporting Technique-Short Form (CHART-SF),[14] will be lower for adults with SB who use MWC and PWC compared with ambulators, regardless of depression scores or shunt history. We also aimed to quantify a number of related variables in this population, such as satisfaction with AT, quality of AT prescribed, secondary complications from AT use, adequacy of wheelchair transportation, and use of other devices such as computer access equipment. We investigated the use of Email, internet, and cell phones as possible modes of communication and interaction not specifically addressed in the CHART-SF.

METHODS

This study was approved by the Institutional Review Board of the University of Pittsburgh. Data were gathered as part of an individual's first or second routine medical visit to the University of Pittsburgh Medical Center Adult Spina Bifida Clinic from August 1, 2005 to April 29, 2008. Data routinely gathered include demographic characteristics, history of hydrocephalus requiring shunting, use of AT such as MWC and PWC or computer access equipment, and satisfaction with wheelchair if used (1–10 ordinal scale with 10 representing highest satisfaction). Further, participants were asked whether they have adequate transportation for their wheelchairs. The Beck Depression Inventory (BDI)[15] was also used to assess depression symptoms. We recorded whether the participants' primary wheelchairs were obtained through a comprehensive AT clinic, defined as a team of individuals including a physical or occupational therapist, vendor, and physician who evaluate the individual and make specific technology recommendations in one setting.

The CHART-SF was used for measurement of functional independence in various domains of social and community participation. This assessment quantifies physical and cognitive independence, mobility, social integration, activity level, and financial status. In each CHART-SF category, a maximum score of 100 correlates with a level of functioning comparable with the average individual without a disability.

For the purpose of this study, data were examined retrospectively by chart review, and if data were incomplete, participants registered in a local research registry were contacted and asked to provide additional data. If they agreed, participants were then asked to provide informed consent and to complete survey information via mail. The data obtained by mail included missing baseline demographic information or minor CHART-SF data such as household income. Because of its time-sensitive nature, the only BDI scores used in this study were those obtained at the time of clinical evaluation when most of the data were collected.

Inclusion Criteria

Participants were between 16 and 80 yrs old with a diagnosis of myelomeningocele or meningocele and who were able to give consent to participate.

Exclusion Criteria

Participants with SB occulta were excluded because functional deficits are often minimal. We did not exclude subjects with cognitive impairments. We allowed caregivers to assist with filling out forms, when needed.

Data Analyses

We assigned participants to the ambulator group if they were able to walk 150 ft and reported minimal to no wheelchair use for basic community navigation. We assigned participants either to the MWC or PWC group if they were not ambulators and according to the device they used most often. Those who primarily used attendant-propelled MWCs or MWCs with power-assist pushrims were classified as MWC users.

α Levels were set a priori at 0.05. Analyses were completed using SAS[16] and SPSS.[17] χ^2 analyses were used to compare groups with respect to shunt history, sex, race, use of ambulation aids, and use of orthoses. We also used χ^2 analyses to compare the two groups of wheelchair users with respect to use of a comprehensive AT clinic and adequacy of transportation. We then used Mann-Whitney *U* statistics to evaluate differences between the two wheelchair groups with respect to number of wheelchair repairs needed and median satisfaction scores.

Individual one-way analysis of variance tests were used to compare mobility groups with respect to age and BDI scores. Individual two-way analysis of variance tests were used to compare groups with respect to the CHART-SF domain scores, with history of shunting as a fixed factor. We used Tukey's b post hoc analyses to determine which groups differed and to correct for multiple comparisons, where statistical significance was found among groups.

Wheelchairs were classified into quality groups based on Centers for Medicare and Medicaid coding and testing standards.[18–20] MWCs were coded as depot (nonadjustable, heavy chairs intended for temporary use only, such as in airports or shopping centers), lightweight (weigh up to about 34 lbs with adjustable axle and seat dimensions), or ultralight weight (highly customizable, usually weighing less than about 19 lbs). Group 1 power chairs are low-cost chairs with basic seating and nonprogrammable electronics. These chairs last only about 1.5 hrs of use on a battery charge, travel a maximum of three miles per hour, and can only overcome obstacles that are ~20 mm. Group 1 PWCs are not usable outside of a person's home because of functional capacity, safety restrictions, and battery capacity and are generally not recommended if the primary purpose is for completion of activities of daily living. Group 2 PWCs are indoor and outdoor wheelchairs with programmable controllers. However, these devices are not usually intended for individuals who depend on powered mobility throughout the day to accomplish all of the activities of daily living. These devices are also not intended for individuals who require more than one power seating function or who cannot use a traditional joystick to drive their wheelchair. Group 3 PWCs are useful both indoors and outdoors, have programmable controllers, and can be fit with two or more power seat functions. Group 3 chairs are typically recommended for individuals who will spend most of the day in their wheelchairs. Group 4 PWCs are those for bariatric patients or for use over rugged terrain.

Analysis of variance statistics were used to evaluate differences in CHART-SF scores with respect to wheelchair quality groups, using Tukey's b for post hoc analyses when needed and to correct for multiple comparisons. χ^2 analyses were used to evaluate associations between satisfaction and quality, AT clinic use and quality, and AT clinic use and satisfaction.

RESULTS

Data from a total of 208 participants were used in this analysis (ambulator, $n = 84$; MWC, $n = 82$; PWC, $n = 42$). Average age was 34.0 ± 10.8 yrs. Females comprised 55.3% of the participants. Five participants were African-American, one was Asian-American, three participants categorized themselves as "other" or more than one ethnicity, and the rest were Caucasian. Average BDI total score

TABLE 1 Mobility groups, CHART scores, and baseline demographics

	Ambulators		Manual Wheelchair Users		Power Wheelchair Users		
	Mean	SD	Mean	SD	Mean	SD	*P*
n (%)	84 (40.4)		82 (39.4)		42 (20.2)		
Age	33.68	10.42	32.79	10.60	36.74	11.56	0.147
Total BDI score	11.41	14.05	10.14	15.61	13.03	13.70	0.664
CHART domains							
Physical independence	82.67	36.06	60.44	43.56	39.71	43.94	<0.0001
Cognitive independence	79.11	27.58	57.26	32.63	47.40	32.39	<0.0001
Mobility	80.80	20.34	67.16	22.05	60.58	27.56	<0.0001
Occupation	63.74	38.10	47.33	38.41	35.36	33.78	0.002
Social integration	67.88	27.96	56.89	31.54	55.45	32.51	0.225
Economic	68.06	33.07	62.92	36.52	61.42	34.01	0.893
Females, *n* (%)	47 (56.0)		46 (56.1)		22 (52.4)		0.914
Using orthoses, *n* (%)	39 (46.4)		19 (23.2)		10 (23.8)		0.010
Using walk aids, *n* (%)	49 (58.3)		39 (47.6)		17 (40.5)		0.568
With history of shunting, *n* (%)	43 (51.2)		77 (93.9)		37 (88.1)		<0.0001
Using comprehensive AT clinic, *n* (%)			35 (42.7)		24 (57.1)		0.312
Without adequate transportation, *n* (%)			47 (57.3)		16 (38.1)		0.161
Median wheelchair satisfaction score (range)			7 (0–10)		7 (0–10)		0.924
Median number of WC repairs (range)			0 (0–30)		0 (0–6)		0.791

was 11.2 ± 14.6, which corresponds with "mild depression." The MWC group contained one subject in an attendant propelled chair and one subject with power-assist pushrims.

Table 1 displays results by mobility group. Mobility groups did not differ significantly by age, sex, race ($P = 0.348$), use of ambulatory aids, or BDI total scores. However, mobility groups did differ significantly in shunt history ($P < 0.0001$) because more wheelchair users than ambulators had a history of at least one shunt. The groups also differed with respect to use of orthoses ($P = 0.01$) because more ambulators used orthoses than did participants in the wheelchair groups.

Groups differed significantly with respect to physical independence ($P < 0.0001$), cognitive independence ($P < 0.0001$), mobility ($P < 0.0001$), and occupation ($P = 0.002$) domains of the CHART-SF. Post hoc analyses revealed that all three groups differed significantly in physical independence, with ambulators having higher scores than MWC users, who in turn had higher scores than PWC users. Further, in the domains of cognitive independence, mobility, and occupation, wheelchair users had significantly lower scores than ambulators. Mobility groups did not differ in social integration or economic self-sufficiency domains. However, in these categories, ambulators trended toward having higher scores than MWC users who had higher scores than PWC users.

Data on other AT use were collected. Table 2 displays percentages of participants who used computer access devices and mobile phones. Also, Figure 1 shows the reasons why participants used the internet.

Only 38% of PWC users and 57% of MWC users reported having adequate personal transportation for their wheelchairs. Refer to Table 3 for a listing of the types of personal transportation available to wheelchair users. Only 8% of wheelchair users

TABLE 2 Use of computer access devices and mobile phones

	n	Percent
Computer at home	141	67.8
Computer outside home	79	38.0
Alternative computer access devices	4	1.9
Modified keyboards	3	1.4
Modified mouse	1	0.5
Mouth stick	1	0.5
Typing orthosis	1	0.5
Mobile telephone	135	64.9

Groups are not mutually exclusive, and so percentages do not sum to 100%. Total cohort is 208 subjects.

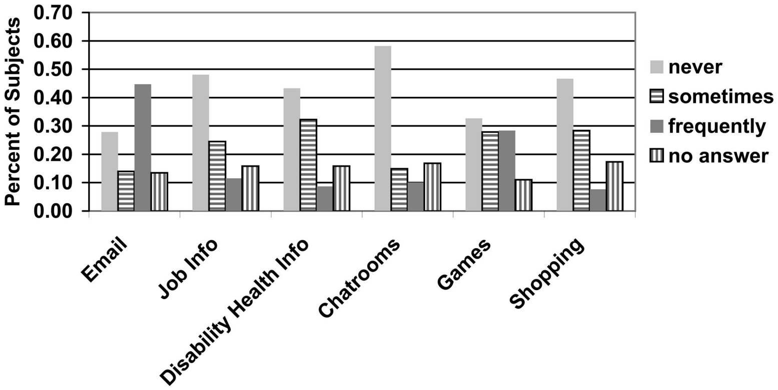

FIGURE 1 *Percentage of subjects using the internet for a variety of purposes.*

reported independence in driving their own vehicle compared with 31% of ambulators. No differences were found by mobility groups regarding adequacy of transportation or use of a comprehensive AT clinic. A total of 43% of MWC users and 57% of PWC users reported getting their wheelchairs from a comprehensive multidisciplinary AT clinic. Wheelchair satisfaction scores were similar among MWC and PWC groups (Table 1).

Table 4 displays the types of bracing and walk aids used by study participants, as well as problems encountered. More than 60% of individuals attributed at least one episode of skin breakdown to their braces. Table 4 also lists types of power features present on PWCs and problems encountered by wheelchair users because of repair issues.

Of 124 wheelchairs used by study participants, 90 makes and models (72.6%) were identified (Table 5). MWC quality was significantly associated with the CHART-SF domains of physical independence ($P = 0.024$), mobility ($P = 0.001$), occupation ($P = 0.012$), and social integration ($P = 0.045$), but not with the other two domains. PWC quality was not associated with any CHART-SF domains. No significant associations were found between wheelchair quality and satisfaction or use of an AT clinic. However, those who attended an AT clinic tended to have higher satisfaction scores (median score of 7) than those who did not attend an AT clinic (median score of 6). The most common MWC prescribed by far was the Quickie II ($n = 41$, or 63.1% of identified MWC); however, PWCs varied over a wide range of makes and models.

TABLE 3 Transportation of wheelchair users

Wheelchair Users	*n*	Percent
Have sport utility vehicle	22	17.7
Have van	34	27.4
Have truck	1	0.8
Drive a vehicle independently	16	12.9

Groups are not mutually exclusive, and so percentages do not sum to 100%. Total cohort of wheelchair users is 124 subjects.

DISCUSSION

No center for care of the adult with SB existed in our area between the closing of one clinic in 2003 and our opening in 2004. The clinic started seeing large numbers of patients in 2005, commensurate with the start of this study. Thus, this study included mostly new patients: those transitioning from pediatric care to adult care and also adult patients who were previously discharged from the pediatric clinic and who had no comprehensive rehabilitation care for several years. Thus, continually tracking these individuals will be vital to determine whether better access to comprehensive rehabilitation care and multidisciplinary AT evaluations influence long-term outcomes.

Our study revealed that almost 60% of individuals with SB use wheelchairs, consistent with that reported by Johnson et al.[7] and higher than that seen in other studies.[21–23] Johnson et al. reported that 35% of adolescents and young adults in their study used braces,[7] which was consistent with our findings. One other Taiwanese study[24] evaluated 39 individuals with SB and found a lower rate of wheelchair use and higher use of braces, but the authors note this may be because of funding issues and cultural stigma of wheelchairs in Taiwan. Johnson et al. also reported that 23% of their participants used ambulatory aids.[7] Our figure of 68% was possibly higher because we included devices that were not only used for ambulation but also to assist with transfers.

Not surprisingly, wheelchair users were more likely to have had a shunt because functional independence is negatively associated with hydrocephalus.[10] However, after controlling for hydrocephalus, we still found lower physical independence scores in

TABLE 4 Walk aids, orthoses, and wheelchair issues

	Yes	Percent	Problems from Wheelchair Repair Issue	Yes	Percent	No	Percent	No Answer	Percent
Walk aids									
Cane	12	5.8	Getting stranded	13	10.5	94	75.8	17	13.7
Quad cane	3	1.4	Getting injured	7	5.6	96	77.4	21	16.9
Walker	13	6.3	Absent from work or school	9	7.3	95	76.6	20	16.1
Forearm crutches	73	35.1	Missing medical appointment	5	4.0	98	79.0	21	16.9
Axillary crutches	25	12.0		—	—	—	—	—	—
Total	126	60.6							
	n	Percent	Power Wheelchair Features						
Orthoses			Tilt	14	33.3	24	57.1	4	9.5
Metal	16	7.7	Recline	14	33.3	24	57.1	4	9.5
Plastic	47	22.6	Elevating legrests	21	50.0	16	38.1	5	11.9
Type unspecified	5	2.4	Seat elevator	5	11.9	32	76.2	5	11.9
Total	68	32.7							
Problems with orthoses									
Skin breakdown	43	63.2		—	—	—	—	—	—
Swelling affects fit	25	36.8		—	—	—	—	—	—

MWC users and even lower scores PWC users, indicating an increasing need for more hours of assistance for personal care and self-transport. Mobility scores, as hypothesized, were lower for wheelchair users than ambulators regardless of shunt history, indicating low daily activity levels, including fewer hours out of bed per day, fewer days out of the house per week, and fewer nights spent away from home.

The occupation domain evaluates time spent in paid work, schooling, homemaking, home maintenance, and recreational activities. In general, better ambulatory status is thought to increase the probability of work participation.[25–27] However, in our study even though ambulators scored much higher than both wheelchair user groups regardless of shunt history, they scored markedly lower than the average, nondisabled person in this functional area (a score of 100 indicates engagement in vocational tasks full time). Because both the occupation and mobility categories evaluated daily and weekly activity levels, low scores in these areas support earlier studies[2,3] that found a high prevalence of sedentary lifestyles in individuals with SB. A decrease in educational achievement has been documented among people with childhood disabilities.[28] However, limited data exist on educational and employment outcomes in SB, with reports of 14%–85% attending or graduating from high school or college[22,26] to ~29% being competitively used.[26,29] One Dutch study found that wheelchair dependence may be significantly associated with the need for special secondary education.[30] Our study indicates that educational and employment barriers are most severe for those using wheelchairs. However, more research is needed to determine whether the barriers are physical, attitudinal, or cognitive.

TABLE 5 No. wheelchairs in each quality category

	Manual Wheelchairs	Power Wheelchairs
Depot	2	—
Lightweight	4	—
Ultralight	59	—
Group 1	—	2
Group 2 (≤1 power feature)	—	6
Group 3 (≥2 power features)	—	16
Group 4 (bariatric)	—	1
Missing data	17	17
Total	82	42

Our findings of reduced cognitive independence among all wheelchair users compared with ambulators correlate with previous findings[11] that wheelchair users demonstrate reduced nonverbal and perceptual organizational skills. The cognitive independence domain evaluates remembering, decision making, and judgment at home and in the community. Because the differences in scores in this domain were present even when controlling for hydrocephalus, cognitive deficits severe enough to impair memory, decision making, and judgment seem to be present even in participants with mild or no history of hydrocephalus. However, this study confirms the notion that those who use wheelchairs also tended to rely on others for cognitive assistance more than do ambulators, which may help explain problems seen in social integration, education, and employment.

One of the most striking findings in our study was the markedly reduced social integration scores for all three groups. This domain captures information about the home environment, roommates, key relationships, and typical interactions with friends, business contacts, and strangers. Of all the CHART-SF domains, this one is arguably the most dependent on reciprocal interactions with other members of society. Ambulators, MWC users, and PWC users all scored far below the level considered average for social integration of able-bodied individuals. Adults with SB who ambulate independently often have short stature, use braces or orthoses, or have other indicators of disability. Therefore, one possible explanation for the low socialization scores in all groups is, regardless of mode of mobility, that individuals with disability are often isolated by limited acceptance and inclusion offered by other members of society. Whether an individual uses a wheelchair or has another indicator of disability, society's response to that individual may be uniformly limiting or exclusive. As a result, a pattern of social avoidance and even learned helplessness may develop in childhood in those with SB.

Limited access to computers at home was also a finding of this study, which may influence employability. However, even when individuals had home internet access, they rarely used it for job or health information. Social networking through chatrooms was also unpopular for this age group, lending some additional support to the notion that barriers to social integration and forming personal relationships are more than just physical. Mobile telephones and, to a lesser extent, Email were commonly used by our participants, and future research should explore their potential to improve social integration.

Employment and social integration may also depend on reliable transportation. Driving requires higher order processing and visual organization skills.[27] The availability of modified vehicles, financing, vocational rehabilitation programs, and social and family support are needed to create successful drivers.[31] This study demonstrates that access to adequate transportation for those in wheelchairs is severely limited. All mobility groups also scored quite low in the economic domain, suggesting that reduced economic self-sufficiency and increased medical costs apply to all individuals, regardless of mobility status or equipment used.

Although depression did not explain differences in CHART-SF scores because of statistically similar scores across all mobility groups, the average BDI score of participants corresponded with mild depression and may explain why some CHART-SF scores were low across all groups. High variability in scores was noted, and significance of results did not change when three outliers were excluded. A previous study has shown that adolescents and young adults are at risk for depressed mood, low self-worth, and suicidal ideation,[32] but a paucity of research exists evaluating how depression may affect mobility and community integration.

Our study showed that the number of problems related to wheelchair durability were low, and most participants received high-quality wheelchairs regardless of whether they attended an AT clinic. However, those who attended an AT clinic tended to be more satisfied with their equipment. The functional discrepancy between ambulators and wheelchair users in this study is not likely caused as much by provision of lower quality or less durable wheelchairs as by depression or other physical or psychosocial barriers. Nevertheless, appropriately customized wheelchairs make mobility more efficient[33] and may partially explain higher satisfaction scores of those attending AT clinics.

Ultralight weight MWCs, compared with lightweight or depot chairs, are typically recommended because they are more durable,[34] put the user at lower risk for repetitive strain injuries,[35] and are therefore associated with more positive quality-of-life measures.[36] Frames can either be rigid, with the option of a folding backrest, or have a cross-brace that allows for collapse of the chair when the user pulls up on the seat. Rigid frames tend to be lighter, which results in more efficient propulsion,[35] and can be loaded into the passenger seat by an independent driver. The user transfers into the driver's seat, removes the wheels, and collapses the backrest. Collapsed cross-brace chairs, on the other hand, are typically transported either in the back seat or trunk of a car and may limit independent driving unless the user has an assistant or can partially ambulate as well as load and unload the wheelchair.

The Quickie II is an ultralight weight chair with a cross-brace frame. More than 60% of our participants in MWCs used this wheelchair. The Quickie II, although not the best frame for independent drivers, is one of the few ultralightweight MWCs that is covered by third-party payers and can be fitted with adjustable and removable leg rests. Individuals with SB often have short leg lengths that are difficult to accommodate with solid frames. The low rate of independent driving and reported lack of adequate transportation of wheelchairs in this population, however, point to the need to consider an individual's potential to drive independently when choosing a frame and underscore another need for comprehensive AT clinic assessments.

More research is needed to develop more product lines that can accommodate the anthropomorphology of people with SB but still have the biomechanical benefits of a rigid frame. PWC features such as tilt, recline, and elevating leg rests may be appropriate for many individuals with SB because of the many medical conditions for which these features are prescribed.[37] Fewer than 50% of PWC users had a full complement of power features. The use of seat elevators can improve the ability of individuals to transfer between different surface heights, improve overhead activities of daily living and reaching tasks, and enhance communication with individuals who are standing,[38] particularly useful for those with SB because of their short stature. However, reimbursement for power features, especially seat elevators, is often difficult to obtain and may impact social integration measures. Our future goal is to follow this cohort of individuals as they access our comprehensive AT clinic to determine whether their functional status improves when their equipment customization is optimized. Our findings support the recommendation that thorough evaluations by multidisciplinary teams experienced in AT prescription be performed for those with SB because their seating and positioning needs are complex.[8]

The limitation of our study was that it was a single-site study that used self-reporting of data. However, this is the only study that we are aware of that links mobility status with socialization and identifies key areas of future research. We are currently collaborating with other sites to expand our data collection in other geographic regions.

In summary, this study found that individuals with SB who use wheelchairs have lower daily home and community activity levels compared with individuals with SB who ambulate and that overall most individuals with SB have low social integration and economic self-sufficiency scores, regardless of whether they use wheelchairs. These findings were not explained by wheelchair quality because most participants were prescribed high-quality devices. Additional research, especially from multiple centers of care, is needed to identify specific barriers to social integration within this population, especially with regard to the impact of depression.

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