Assistive Technology Use Among Adolescents and Young Adults With Spina Bifida

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Objectives. We sought to determine the use of assistive technology among a population of individuals with spina bifida.

Methods. We performed a descriptive analysis of individuals aged 13 to 27 years diagnosed with myelomeningocele (n = 348) using data obtained from an existing database at Children's Hospital and Regional Medical Center, Seattle, Washington. We summarized disease characteristics, utilization of assistive technology, community and self-care independence, and other variables.

Results. Eighty-four percent of the respondents lived with at least 1 of their natural parents. Fifty-seven percent used wheelchairs, 35% used braces, and 23% used walking aids. Independent self-care was a common skill, but 72% reported limited participation in structured activities. Half were aged 18 years or older; of those, only 50% had completed high school and 71% were unemployed. Those aged younger than 18 years were all still in school (100%).

Conclusions. Adolescents and young adults with spina bifida rely on assistive technology and specialized care routines to maintain their health. Assistive technology use for mobility is common; little is known about secondary complications associated with use of these technologies or the use of assistive technology to address learning disabilities and other societal barriers. Underutilization of assistive technology could delay successful transitions to independent living and community participation. (*Am J Public Health.* 2007;97:330–336. doi:10.2105/AJPH.2004.050955)

Spina bifida and anencephaly are the most commonly occurring neural tube defects and affect approximately 2500 births per year in the United States, though rates have been steadily declining for decades.[1–3] Most cases (70%) of spina bifida and anencephaly, as well as other birth defects, can be prevented by consumption of at least 400 micrograms (μg) of folic acid by women of childbearing age prior to conception and during pregnancy.[1] Since the implementation in 1996 of folic acid supplementation of enriched grain products, the prevalence of neural tube defects has declined by as much as 26%.[4,5]

Although it is logical to assume that individuals with spina bifida are candidates to use assistive technologies, comprehensive reviews of their actual use and effect on performance have been relatively sparse. No data are available indicating the prevalence of use for different types of assistive technology by people with spina bifida. In addition, few rigorous evaluations of the public health benefits and rehabilitation outcomes from use of assistive technology by people with spina bifida have been conducted. Based on our review of the literature and clinical experience, we expect that individuals with spina bifida utilize assistive technology to enable or enhance mobility, manipulative skills, personal care independence, and cognitive performance.

Mobility and Community Participation

From our review, we observed that, as children with spina bifida age, they transition from walking to wheeling or a combination of mobility techniques depending on context.[6] Those with higher-level lesions might be expected to ambulate initially, but many cease walking after reaching age 3 to 4 years and shift to use of wheeled mobility.[7,8] Transition to wheeled mobility increases the risk of wear and tear on upper limbs because of the stress and strain of wheelchair self-propulsion.[9] This may be further complicated by device vibration from the terrain, though the risk of upper-extremity damage can be mitigated and economy of energy enhanced through skills training.[10,11]

To actively participate in the community, individuals with spina bifida extend their mobility through driving and use of public transportation, but community mobility can be problematic for wheelchair and other adaptive mobility device users.[12] Andrén and Grimby[13] found that adults aged 24–43 years with spina bifida in Sweden experienced difficulty with mobility outdoors and when using public transportation because of interactions between personal assistive technology and inaccessible environments.

Mobility is of primary importance for participation in the community, but limitations in hand function and manipulation skills may also be problematic for individuals with spina bifida. When individuals have difficulty performing personal care, such as clean intermittent catheterization (use of a flexible catheter to drain the bladder), managing external collection devices, and digital stimulation for bowel programs (initiation of a bowel movement by insertion of the index finger into the anus to empty one's rectum), additional accommodations (including use of personal assistants or help from others) may be required. This results in reduced independence in activities of daily living, and the need for specialized personal care routines.[13]

Difficulty with fine-motor skills, such as handwriting, requires assessment and adaptation, and provides an opportunity for utilization of assistive technology. Manipulation difficulties may be further complicated by cognitive deficits that are characterized by short attention span, learning disabilities, intellectual delay, distractibility, and overall delay in adaptive skill development. Recent studies have confirmed a 50% prevalence rate of specific or general cognitive deficits among individuals with spina bifida and hydrocephalus, and associated enrollment in special education.[14,15] Simeonsson et al.[16] noted that challenges with tactile perception,

auditory concentration, visual perceptual organization, and visual–motor integration are seen in a disproportionate number of children with spina bifida. In addition, a growing number of young adults with spina bifida are facing challenges with respect to education, vocation, housing, and relationships.[14]

Assistive technology has often been recommended to enhance performance and advance independence outcomes in daily living, community participation, education, and employment, primarily with reference to mobility and bladder or bowel care. The selection of mobility aids such as wheelchairs, walking aids (e.g., crutches), or lower-limb braces (e.g., ankle–foot orthosis) is primarily determined by lesion level. Bartonek and Saraste[17] evaluated a series of patients with spina bifida and contrasted those who achieved expected ambulatory function outcomes with those who did not. They found that although lesion level predicted the type of mobility aid, it did not predict the successful use of that aid. Rather, a wide range of other factors seemed to influence successful use of mobility devices.

Self-Care and Cognitive Support

With regard to bladder and bowel care, clean intermittent catheterization and timed bowel programs are the most frequent solutions with varying degrees of successful day-to-day management.[18] Less successful implementation of bowel and bladder routines leads to increased risk for secondary complications and adverse psychosocial complications.[19,20]

Assistive technology to support cognitive functioning has also been used for children with spina bifida. These technologies include electronic time prompts and alarm avoidance to improve performance of wheelchair push-ups,[21] memory aids to assist in health maintenance routines,[22] word-prediction software to improve the rate and accuracy of text entry on computers,[23] and hand-held electronic predictive spelling aids.[24] Although these interventions appear promising, long-term efficacy for any device has not been established.

Barriers to Assistive Technology Use

In a survey of individuals aged 16 to 25 years with motor disabilities (including spina bifida) regarding barriers encountered with use of assistive technology, researchers in Sweden found that respondents most frequently complained about lack of access to computers and software at school and home, to technical aids for leisure time, and to mobility devices.[25] Although half of the participants were satisfied with the level of technical assistance they received, half reported they received too little technical support, information, and training to effectively use assistive technology independently. This resulted in a continued need for personal assistance from parents or aides. The subjects also reported that as they transitioned into adult life, they felt increasingly isolated and lonely and perceived a social discrimination that resulted in their exclusion from community participation.

It is important to understand the impact of assistive technology on health and function. However, measuring outcomes of assistive-technology use is complex. Complex interactions between physical, functional, psychosocial, and quality-of-life variables all contribute to either technology use or abandonment.[26] The positive benefits of enhanced function afforded by assistive technology may not outweigh dissatisfaction with its appearance, difficulties with maintenance, cost, and other factors.

Critical Transitions

The transition from childhood to young adulthood is a demanding developmental stage. During this time, individuals encounter significant challenges as they move from high school to postsecondary education or employment. There is also the necessary transition from the pediatric to the adult health care system. During this transition, young adults with disabilities will encounter changing roles and expectations. In addition, their repertoire of skills, competencies, and needs are often not well matched to the requirements of the adult world.[27]

Shultz and Liptak[28] proposed that characteristics such as high self-esteem, positive social orientation, warm and cohesive family life, friendship networks, and previous success in coping with stressful experiences are helpful for this transition. Adolescents with spina bifida may have fewer opportunities to develop these characteristics within the context of their complex health, physical, cognitive, and social challenges. Low engagement in typical activities of adolescence such as decisionmaking, friendship activities, and household responsibilities are likely to impair successful transition to adulthood, particularly in terms of self-management and employment.[29]

Adolescents and young adults with disability who rely on assistive technology are often transitioned toward unclear or tentative postsecondary education, employment, and independent living outcomes.[30] In the kindergarten-through-12th-grade educational and pediatric medical environments, adolescents may have access to a broad range of support for assistive technology and other activities. In the postschool and adult medical environments, assistive technology and related services are less well integrated and less available. In addition, assistive technology support needs may increase even though funding for services tends to diminish.

Advocacy and networking skills are often required to successfully access services, and these may not be well developed in young adults with disabilities. For example, young adults may need to build relationships with vendors who sell assistive technology and other experts to receive the support they need for their assistive technology. A recurrent cycle of technology evaluation, selection, acquisition, training, use, and modification may lead to frustration because of changing needs, device failure, or new options and features of technology that necessitate retraining. Although expectations about the value of assistive technology vary across adolescents with various types of disability, most hope for greater access to assistive technology and, with it, a higher level of social acceptance in the community.[30]

The purpose of this research was to examine a historical database for information about adolescents and young adults with spina bifida to gain a better understanding of their use of assistive technology and level of community participation. The results of this descriptive study will define goals for more in-depth future research into the use of and satisfaction with assistive technology among adolescents and young adults with spina bifida and the relationships between assistive technology, quality of life, and secondary conditions that emerge while these individuals function and age.

METHODS

Data were obtained from a cross-sectional sample drawn from an existing longitudinal database maintained at Children's Hospital and Regional Medical Center, Seattle, Washington. The Patient Data Management System is a cumulative database that contains serial examination information on all children seen at Children's Hospital and Regional Medical Center with spina bifida beginning in 1960. Data were collected on multiple aspects of their health care: primary and secondary conditions, developmental milestones, surgical procedures and hospitalizations, utilization of mobility devices and other assistive technology, related physical and occupational therapy services, intellectual and educational assessment, and other variables. The institutional review board of Children's Hospital and Regional Medical Center approved all procedures for this study.

We selected individuals from the database aged between 13 years and younger than 28 years as of December 1, 2003, with a diagnosis of myelomeningocele (n=348). A cross-sectional data set was created using the most recent record for each individual for each type of assessment (i.e., demographic, physical therapy, occupational therapy, etc.). Descriptive statistics were generated for nonmissing data to determine the prevalence of assistive technology use and to describe the biological, demographic, and functional characteristics of the study sample. To examine personal care independence, we created a composite variable by calculating the sum of each person's reported ability to do 8 self-care items independently: dress completely, prepare meals, make a sandwich, perform hygiene, use the toilet, do own laundry, wash hands without help, and bathe alone (each coded 1=pass, 0=fail). This total score was divided into low (0–2), medium (3–5), and high (6–8) personal care independence.

Characteristics were examined for 2 groups to account for potential differences that might exist between adolescents (aged 13–17 years) and young adults (aged 18 years and older).

TABLE 1—Demographic and Diagnostic Characteristics of Adolescents and Young Adults With Spina Bifida (n=348): Patient Data Management System Database, Children's Hospital and Regional Medical Center, Seattle, Washington, December 2003

	Age Group, y		
	13–17 (n=178),[a] no. (%)	≥18 (n=170),[a] no. (%)	Total (n=348),[a] no. (%)
Gender			
Male	83 (47)	97 (57)	180 (52)
Female	93 (53)	72 (43)	165 (48)
Lesion level			
Thoracic/high lumbar	40 (23)	62 (36)	102 (29)
Lumbar (L3–5)	62 (35)	63 (37)	125 (36)
Sacral	66 (37)	36 (21)	102 (29)
Other/mixed	9 (5)	9 (5)	18 (5)
Shunt in place			
Yes	119 (67)	118 (69)	237 (68)
No	59 (33)	52 (31)	111 (32)
Age at shunt placement			
≤6 m	111 (93)	110 (93)	221 (93)
>6 m	8 (7)	8 (7)	16 (7)
Living situation			
Lives with natural parents	153 (93)	118 (75)	271 (84)
Other living situation[b]	12 (7)	39 (25)	51 (16)
Current education program			
None	0 (0)	37 (29)	37 (13)
Special education	44 (27)	44 (35)	88 (30)
Regular education with a delay >2 grades	15 (9)	2 (2)	17 (6)
Regular education within 2 grades	70 (43)	22 (17)	92 (32)
Regular education with resource room	34 (21)	11 (9)	45 (16)
Higher education or vocational and other training	1 (<1)	10 (8)	11 (4)
Completed education			
Less than high school	159 (95)	46 (28)	205 (62)
High school	2 (1)	82 (50)	84 (25)
College degree	0 (0)	11 (7)	11 (3)
Vocational or workshop training	0 (0)	12 (7)	12 (4)
Ungraded special education	7 (4)	14 (8)	21 (6)
Employment status			
Employed	14 (9)	47 (29)	61 (20)
Unemployed	136 (91)	113 (71)	249 (80)

[a]Numbers may not add up to sample size because of missing data. Percentages in each category are based on reported cases.
[b]Includes living with adoptive parents, with foster parents, in a nursing home, and with relatives.

RESULTS

The study sample was nearly evenly divided between males and females (Table 1) and ages ranged from 13 to 27 years (mean age=18 ±2.46 years). Sacral lesions were most common (37%) among adolescents, whereas mid and low lumbar-level lesions were most common (37%) among young adults. Overall, 68% had a shunt in place, of whom 93% had received the shunt before they were aged 6 months.

At the time of their most recent assessment, 93% of the adolescents lived with 1 or both natural parents, whereas the same was true for only 75% of the young adults. All individuals aged younger than 18 years were in some type of education program (Table 1). Forty-three percent of the adolescents attended regular education classes within 2 grades of their

TABLE 2—Assistive and Medical Technology Use by Adolescents and Young Adults With Spina Bifida (n = 348): Patient Data Management System Database, Children's Hospital and Regional Medical Center, Seattle, Washington, December 2003

	Age Group, y		
	13–17 (n = 178),[a] no. (%)	≥18 (n = 170),[a] no. (%)	Total (n = 348),[a] no. (%)
Wheelchair			
Manual	84 (48)	95 (56)	179 (52)
Electric	7 (4)	11 (7)	18 (5)
None	85 (48)	63 (37)	148 (43)
Braces[b]	65 (37)	55 (32)	120 (35)
Walking aids[c]	41 (23)	39 (23)	80 (23)
Bowel program[d]	155 (88)	154 (92)	309 (90)
Bladder program[e]	159 (95)	164 (99)	323 (97)

[a]Numbers may not add up to sample size because of missing data. Percentages in each category are based on reported cases.
[b]Includes THKAFO, HKAFO, KAFO (where T = trunk, H = hip, K = knee, A = ankle, F = foot, 0 = orthotic), supramalleolar orthotic, UCB (named for University California, Berkeley) insert, twisters, metal or plastic, and braces for 1 or both legs.
[c]Includes canes, crutches, and walkers.
[d]Includes digital stimulation, timed program, enema, suppository, ostomy, and others.
[e]Includes diaper, pants, catheter, timed program, external collector, diversion, and others.

expected level, 27% were in special education, 9% were in regular education with more than 2 years delay, and 21% were in regular education placements with a resource room, where students were offered the opportunity for additional educational services outside the regular classroom. Of the young adults, 35% were still attending special education and 17% were in regular education classes within 2 grades of expectation. Only 50% of the young adults had completed high school and only 14% had completed college degrees or vocational or technical training. (Some students may have reported that they had graduated from high school when they were still receiving special education services.) Among the young adults, 71% reported no current employment.

More than half of the individuals (57%) used manual or electric wheelchairs (Table 2). In addition, 35% used braces and 23% used some form of walking aid to assist with ambulation (Table 2). Ninety percent of individuals reported some kind of stool management program (digital stimulation, timed program, enema, suppository). Furthermore, 97% reported a program for bladder management (clean intermittent catheterization, diapers, incontinence pants, external collector). These characteristics were similar for both age groups.

Personal care independence was similar for both age groups. The majority of individuals reported moderate to high independence when it came to self-care activities such as eating, washing, and dressing without help (Table 3).

Thirty percent of the adolescents reported independent ambulation without aids or braces outside the home; this was true for only 16% of the young adults (Table 3). A greater percentage (36%) of young adults was wheelchair independent compared with the younger group (25%). More than half (53%) of the young adults used independent transportation (either automobile or public transit), compared with only 33% of the adolescents.

Despite apparently satisfactory mobility with or without aids, 72% reported no participation in structured activities and 63% reported no participation in unstructured activities (Table 3).

Limited information was available regarding the developmental status of the individuals in the database. For approximately half of the sample, verbal IQ (mean = 87.28 ±18.02) and performance IQ (mean = 82.79 ±17.48) scores were available. Although the means scores were not in the range of developmental disability, they fell below the 16th percentile compared with the scores of age-matched peers in the general population (e.g., mean IQ score = 100 ±15 for Wechsler instruments).

DISCUSSION

Spina bifida is a relatively uncommon condition and the resulting disability is variable depending on lesion level, shunt history, cognitive resources, secondary conditions, and psychosocial and environmental variables. Few databases exist that allow detailed examination of such a large sample of individuals over time. In this study, we used a cross-sectional sample to describe the biological, demographic, and functional characteristics of adolescents and young adults with myelomeningocele. This unique opportunity provides the background data necessary to conduct further research on assistive technology, secondary conditions, and other areas important to people with spina bifida.

The results of this study also provide a method for comparing experiences of adolescents and young adults with spina bifida to those of peers with other kinds of disabilities as well as with developing peers without disabilities. For example, the employment rate for individuals of working age in the database is approximately the same as that reported by the National Council on Disability on the basis of census data for adults with disabilities.[31] However, the unemployment rate is mediated to some degree by the 14% who are attending some type of postsecondary education or training. Given that most people with disabilities are able and would prefer to work with appropriate supports, including assistive technology, and that employment confers significant advantage in terms of health status, perceived quality of life, and economic well-being, this high rate of unemployment is of concern.[31]

Limitations

In general, information about assistive technology in the database was limited to mobility devices and personal care programs, which reflected the medical model under which these data were collected. A broader range of data with respect to the barriers individuals encounter in their communities, the assets they bring to bear on these barriers, and the compensatory strategies they employ are not currently available. Furthermore, the extent of the role played by assistive technology in the level of independence observed among individuals in this data set with regard

TABLE 3—Personal Care, Mobility, and Community Independence of Adolescents and Young Adults With Spina Bifida (n = 348): Patient Data Management System Database, Children's Hospital and Regional Medical Center, Seattle, Washington, December 2003

	Age Group, y		
	13–17 (n = 178),[a] no. (%)	≥18 (n = 170),[a] no. (%)	Total (n = 348),[a] no. (%)
Personal care independence			
Low	49 (30)	36 (23)	85 (27)
Medium	59 (36)	67 (43)	126 (39)
High	57 (35)	52 (34)	109 (34)
Usual locomotion			
Wheelchair independence outside home	43 (25)	60 (36)	103 (30)
Can travel long distances with braces, aids, or wheelchair	17 (10)	12 (7)	29 (9)
Uses aids or braces, no wheelchair	28 (15)	29 (17)	57 (17)
Complete function without braces or aids	52 (30)	27 (16)	79 (23)
Other locomotion[b]	35 (20)	38 (23)	73 (21)
Extent of mobility			
Goes out into neighborhood alone	51 (35)	29 (19)	80 (27)
Independent transportation (automobile or public)	49 (33)	82 (53)	131 (44)
Limited mobility[c]	47 (32)	43 (28)	90 (30)
Able to participate in structured activities			
Yes	53 (30)	42 (26)	95 (28)
No	124 (70)	122 (74)	246 (72)
Able to participate in unstructured activities			
Yes	69 (39)	60 (36)	129 (38)
No	107 (61)	108 (64)	215 (63)

[a]Numbers may not add up to sample size because of missing data. Percentages in each category are based on reported cases.
[b]Includes being carried, scooting or crawling inside the home, wheelchair, gurney, use of braces inside home, and home ambulation only.
[c]Includes going out of the house with parent or guardian only and limited to yard or nearby neighborhood alone.

to hygiene, eating, dressing, and community participation is unclear. Information regarding assistive technology use in school or work environments is also not captured in these data.

Analysis of these data was limited by time (age) differences between the most recent assistive technology and medical technology assessments and demographic updates (i.e., education, employment, living status, and so on). Changes may have occurred in an individual's use of assistive technology and the database information may not be current with respect to independent living, employment, or community participation status for some participants. On the basis of age and date of last assessment, we estimate that time differences would only affect 10% of the study sample and would not have a significant impact on our conclusions.

Recent Assistive Technology Developments

There are a number of relatively recent developments in assistive technology that may be presumed to potentially benefit adolescents and young adults with spina bifida. In the area of assisted mobility, a range of lighter-weight, manually propelled wheelchairs are now more commonly available. Power-assisted manual wheelchairs and battery-powered scooters may also provide greater options for future community mobility needs. Although community transit access continues to be problematic, greater availability and use of paratransit services and wheelchair-accessible city bus systems may afford broader access to community activities and supports.

For students with learning disabilities, a variety of compensatory software programs are now available. For example, students with writing difficulties can now use speech-recognition software for text entry. Alternatively, they may use word-prediction software, with correction for words begun with phonetic spelling, to increase the speed and accuracy of writing. Students with reading disabilities can use a variety of software applications to convert text to speech. Memory and other executive-function deficits may be aided with personal digital assistants, text pagers, cell phones with calendar or text page capacity, watches with alarms or calendars, and other tools.[32] No research is available on the prevalence of use of assistive technology to address learning difficulties among youth with spina bifida, and there is no research to support the efficacy of these interventions for this group, so this would be fertile ground for future research. Currently, assistive technology is not available to effectively compensate for those students with overall diminished intellectual resources.

Public Health Implications

The biggest public health priority related to spina bifida is prevention of the disease by use of dietary supplements of folic acid by women of childbearing age. It is estimated that 70% of cases are preventable with this intervention.[1] In addition, reduction in the incidence and severity of secondary conditions and the promotion of health and well-being among individuals with spina bifida is also an important area of focus for public health practitioners.[33] These public health priorities contribute to the broader goals of increasing the independence, productivity, social participation, and quality of life for people with spina bifida.

A recent survey of adults with disabilities in Washington State showed that moderate-to-severe secondary conditions were 2 to 3 times more likely in adults with disability than in adults in general.[34] The most commonly reported secondary conditions included pain, obesity, fatigue, difficulty getting out into the community, falls and injuries, sleep problems, muscle spasms, and bowel and bladder problems. These findings are consistent with the secondary conditions expected and found among those who have spina bifida.[16] Furthermore, though research

has shown that adolescents with physical disability, including those with spina bifida, may be less likely than nondisabled counterparts to smoke, drink, or use drugs, they are much more likely to have unhealthy eating patterns and to engage in sedentary leisure activities that diminish opportunities to maintain fitness.[35]

Although the incidence of spina bifida is on the decline, the number of individuals affected with a childhood disability is on the rise. Individuals with spina bifida could benefit from programs and approaches proposed for use with others who have developmental disability. Ayyangar[36] contended that although conditions resulting in childhood disability are varied, using a general health framework approach to their care and management is most advantageous. A broad focus on anticipatory guidance, growth, development, medical care, psychological and vocational counseling, and resource planning is recommended to address particular challenges. Promoting healthy eating habits, encouraging exercise and socialization behaviors, and strengthening bonds between children with disability, family, and community are essential to minimize disability-related problems in adulthood.

There is variable success with independence and full community participation among those with spina bifida, which may relate to the complexity of the disorder and associated disability management methods, including uses of assistive technology. Although using assistive technology can result in significantly enhanced independence, employment, and life satisfaction, the technology must be carefully matched with the individual to achieve successful outcomes.[37]

Conclusions

A significant number of adolescents and young adults with spina bifida rely on assistive technology and special care routines to maintain their health. They use assistive technology for mobility, but little is known about secondary complications such as musculoskeletal overuse syndromes and other challenges associated with wheelchair and walking-aid use. However, the use of assistive technology to address learning disabilities and other barriers to societal inclusion is not so evident. This underutilization may be delaying or restricting successful transitions to independent living and full participation within the community. Additional research to determine the extent to which assistive technology is used, the impact of assistive technology on daily living and quality of life, and the ways in which assistive technology contributes to secondary conditions in individuals with spina bifida is warranted. From these additional data, recommendations could be made to increase consideration of assistive technology across a broader range of domains. ■

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K.L. Johnson originated the study and led the writing of the article. B. Dudgeon and W. Walker contributed to the interpretation of the data and the writing of the article. C. Kuehn led the data analysis and collaborated in writing the article.

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Human Participant Protection

Approval to conduct this study was given by the institutional review board of Children's Hospital and Regional Medical Center, Seattle, Wash, and was obtained prior to the analysis of this data set.

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