


Sociodemographic Characteristics, Health Literacy, and Care Compliance in Families With Spina Bifida

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Abstract

Children with spina bifida experience varying rates of disease complications and health system overutilization. Data on sociodemographics, urinary tract infection, clean intermittent catheterization, and health system utilization were collected from caregiver-patient dyads. Newest Vital Sign (NVS) and Brief Health Literacy Screen (BRIEF) were administered to evaluate health literacy (HL). In total, 105 dyads completed enrolment with 24.8% versus 12.4% of caregivers scoring poor/marginal on the NVS and BRIEF, respectively. Nearly half on clean intermittent catheterization missed a catheterization over the previous week. Medicaid insurance, parental education, and household income predicted HL ($P < .01$). Over the preceding 5 years, 68.5% visited our hospital's emergency department. Eighteen (25%) visited the emergency department >6 times and 12 incurred charges over \$50 000. Caregivers of children who missed ≥ 4 catheterizations per week had lower NVS scores ($P = .03$). Children with spina bifida represent high utilizers, and consideration of sociodemographic and HL differences is necessary when tailoring care plans.

Keywords

spina bifida, myelomeningocele, health literacy, compliance, utilization

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Introduction

Spina bifida is estimated to occur in 3.5 per 10 000 live births in the United States, with approximately 1460 new cases annually.¹ Although infant survival rates have improved over the last half century, the relative mortality rate among children 6 years and older with spina bifida is still 10 times greater than in children without birth defects.²⁻⁴ Mortality is highest during infancy; however, rates rise again during the adolescent/young adult years.⁵ The average lifetime health care cost associated with spina bifida is estimated at \$635 000 per patient in the United States.⁶ Health-related costs arise from the screening and treatment of disease-specific and associated comorbidities, many of which are modifiable. In children with spina bifida, one third of hospital admissions result from potentially preventable disease complications. Urinary tract infection (UTI), a disease complication that may be reduced with improved self-care, represents the most common diagnosis.⁷ Spina bifida patients are also more likely to utilize emergency

room (ER) and inpatient (IP) services compared with the general population with a rate of 0.83 ER and 0.28 IP versus 0.18 ED and 0.03 IP visits per person-year, respectively. Urinary tract infection is the most common diagnosis.⁸

Although patients with spina bifida in general are at increased risk for health complications, there are also disparities in care and clinical outcomes across sociodemographic groups. In the United States, children of Hispanic origin who have spina bifida show less urinary continence and lower satisfaction with bladder management compared with non-Hispanic children.⁹ In addition, infant mortality rates among Black and Hispanic infants with spina bifida continue to exceed those of

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Whites.¹⁰ Similar ethnic and racial disparities have also been shown in other care-intensive pediatric chronic diseases, emphasizing the need for a better understanding of contributing factors.¹¹⁻¹³ Health literacy, the ability to understand and act on basic health information, has been reported to vary by race and ethnicity and likely affects how easily families are able to navigate the health care system and manage their disease.¹⁴

The Institute of Medicine and the US Department of Health and Human Services identify the need for health literacy research, emphasizing the role it plays in reducing disease and health disparities.^{15,16} A deficiency in parental health literacy likely affects both the adult's ability to perform self-care and their ability to provide necessary care to their children. Furthermore, in teens with special needs, parent health literacy is strongly associated with teen health literacy, potentially negatively affecting the communication between parent, teen, and health care provider.¹⁷ In 2009, a recommendation for action, published in *Pediatrics*, emphasized the importance of health literacy awareness and research. This report discussed the necessity for a better understanding of the relationship between health literacy and disparities so that policy and practice-based interventions can be developed to target those at greatest need.¹⁸ Although there is continued interest in the effects of health literacy on disparities in health and health care, there is currently no data available on these relationships among caregivers of, and patients with spina bifida. Patients with spina bifida are an optimal patient population in which to study these effects due to the exceptionally high level of health system utilization and the compliance with care necessary to preserve their urologic health. This study aimed to investigate the sociodemographic characteristics, health literacy, clean intermittent catheterization (CIC) compliance, UTI history, and health system utilization of patients seen at a large spina bifida clinic, at a tertiary children's hospital in the United States. We hypothesized that health literacy would vary by sociodemographic characteristics and that both would be associated with CIC compliance, UTI rates, and health system utilization.

Methods

Study Population

Participants were recruited from a multidisciplinary clinic at a large free-standing children's hospital that provides care for over 400 patients with spina bifida. Depending on age and disease severity, patients are typically followed every 3, 6, or 12 months with recommended imaging and laboratory investigations.

Inclusion criteria included the diagnosis of spina bifida (myelomeningocele with exclusion of lipomeningocele and meningocele), 0 to 21 years of age, and accompaniment by a parent caregiver. Due to the lack of translation validity for survey material to all potential languages in our community, non-primary English speakers were excluded. After a description of the study and parental verbal consent (child assent when indicated), parent caregivers were provided with survey materials.

Data Collected

Data on sociodemographic characteristics, health literacy, CIC compliance, UTI history, and health system utilization were collected. The Newest Vital Sign (NVS) and Brief Health Literacy Screen (BRIEF) were administered to evaluate health literacy level. NVS is a widely accepted, validated, 6-question tool designed to assess numeracy and health literacy.¹⁹ NVS was administered in person by a trained research assistant, and scores of 4 to 6 were considered adequate while scores of 0 to 3 were considered poor or marginal. NVS evaluates numeracy and health literacy by testing the subject's ability to navigate a food label. The BRIEF is a 4-item, validated health literacy screening tool that is completed by participants and does not require trained administration.²⁰ The BRIEF has shown positive correlation with more time-intensive assessments of health literacy and is recommended as a first-line clinical screen.²¹ The BRIEF is scored on a scale of 4 to 20. Scores >16 were considered adequate while scores 4 to 16 were considered poor or marginal. Unlike NVS, which tests health literacy, the BRIEF evaluates a subject's perception of their own health literacy.

Medical management and compliance were assessed through questionnaires evaluating provider-recommended CIC frequency and self-reported compliance to these recommendations. Parent-reported UTI occurrence over the previous 3 month period was recorded. Health system utilization was evaluated using administrative data extracted from our hospital's data warehouse on ED visits that resulted in either treatment and release or hospitalization within the preceding 5 years.

All study participants were offered the option of immediate completion of study questionnaires in clinic, completion at a later time in person, or online completion of the survey at home. Research Electronic Data Capture (REDCap) was utilized to collect and store results.²² If the online survey completion option was preferred, surveys that required completion in person (NVS) were administered during the clinic visit. This study was approved by our institutional review board with a waiver of written documentation of consent.

Statistical Methods

Patient characteristics were summarized using frequencies and percentages for categorical variables and means and interquartile ranges for continuous variables. Associations between NVS or BRIEF scores and patient sociodemographic characteristics, CIC compliance, UTI history, and health system utilization were assessed using Wilcoxon rank sum tests or Kruskal-Wallis tests. Associations between health system utilization or charges and patient sociodemographic characteristics were also assessed using Wilcoxon rank sum tests or Kruskal-Wallis tests. SAS version 9.4 (SAS Institute Inc, Cary, NC) was used for all statistical analyses.

Results

Between August 2015 and April 2016, 168 families were approached in clinic. Twenty-seven families declined to participate, 14 requested to delay until next visit but were not seen again in clinic during the study enrollment period, and 22 provided incomplete data. A total of 105 caregiver-patient dyads agreed to participate and completed all required surveys within the study period. All data were provided by caregivers about the corresponding patient, which represented the dyad in this study.

Cohort Demographics

The median patient age was 8 years (range = 4 months to 21 years). Forty-seven (44.8%) children were on Medicaid, and there was wide variation in parental education level and total household income. The majority of families identified as White (86.7%; Table 1).

Cohort Health Literacy and Clinical History

Twenty-six (24.8%) parent caregivers scored poor or marginal on the NVS and 13 (12.4%) scored poor or marginal on the BRIEF. The majority (62.9%) of patients were on CIC regimens with the most common regimen being catheterization every 4 to 5 hours. Nearly half (46.9%) of the families on CIC reported missing at least one catheterization during the previous week. Twenty-eight (26.7%) reported at least 1 UTI over the last 3 months defined as requiring a new or change in antibiotic (Table 2).

Cohort ED Visits and Charges

Analysis of ED visits found that 45.9%, 60.9%, and 68.5% of participants visited our hospital's ED over the prior 1, 2, and 5 years, respectively. Over the same

Table 1. Demographic Characteristics of Study Cohort.

Variable	Overall (N = 105)
Female, n (%)	48 (45.7)
Age in years, n (%)	
0-1	13 (12.4)
2-4	19 (18.1)
5-8	24 (22.9)
9-12	15 (14.3)
13-17	22 (21.0)
18-21	12 (11.4)
Primary insurance, n (%)	
Medicaid	47 (44.8)
Private insurance	58 (55.2)
Highest level parent education, n (%)	
Less than a high school diploma	7 (6.7)
High school/GED	23 (21.9)
Some college	22 (21.0)
2-Year college (associates)	18 (17.1)
4-Year college (BS/BA)	25 (23.8)
Master's degree	7 (6.7)
Professional (MD/JD)	3 (2.9)
Total household income, n (%)	
<\$25 000	31 (29.5)
\$25 000 to \$49 999	24 (22.9)
\$50 000 to \$99 999	30 (28.6)
\$100 000 or more	20 (19.0)
Race, n (%)	
White	91 (86.7)
Black or African American	11 (10.5)
Hispanic	3 (2.9)

5-year period, 18 (25%) patients in our cohort visited the ED >6 times and 12 (16.4%) incurred charges (ED visit(s) and associated hospitalization(s) if admitted) over \$50 000 (Table 3).

Predictors of Health Literacy

When associations between parent sociodemographic characteristics and health literacy level were investigated, several statistically significant relationships were detected. Medicaid insurance, lower parental education level, and lower total household income were all significant predictors of poor or marginal health literacy as measured by both the NVS and BRIEF screens ($P < .01$ for all). White parents had higher health literacy than Black or Hispanic parents on the NVS ($P = .02$) but not on the BRIEF ($P = .40$).

Predictors of Clinical Outcomes

No significant associations were identified between ED visits or charges over the previous 1, 3, or 5 years and

Table 2. Health Literacy Scores and Clinical History of Study Cohort.

Variable	Overall (N = 105)
Parent NVS raw score, median (Q1, Q3)	5 (4, 6)
Parent NVS score category, n (%)	
Poor	5 (4.8)
Marginal	21 (20.0)
Adequate	79 (75.2)
Parent BRIEF score, median (Q1, Q3)	19 (18, 20)
Parent BRIEF score category, n (%)	
Poor	3 (2.9)
Marginal	10 (9.5)
Adequate	92 (87.6)
Times per day urinary catheterization, n (%)	
0	39 (37.1)
1	3 (2.9)
2 to 3	10 (9.5)
4 to 5	35 (33.3)
6	10 (9.5)
More than 6	8 (7.6)
How often each week catheterization missed, n (%)	
1-3 times	27 (40.9)
4-6 times	2 (3.0)
7 or more times	2 (3.0)
Never	35 (53.0)
UTIs in last 3 months, n (%)	
0	77 (73.3)
1 to 2	24 (22.9)
3 to 4	4 (3.8)

Abbreviations: NVS, Newest Vital Sign; BRIEF, Brief Health Literacy Screen; UTI, urinary tract infection.

health literacy screens (data not shown). Parent caregivers of children who missed 4 or more catheterizations per week had lower NVS scores than parents whose children missed fewer or no catheterizations ($P = .03$), but this finding did not hold for the BRIEF ($P = .27$; Table 4).

Associations between family sociodemographic characteristics and ED visits, over the previous 1, 2, or 5 years and charges over the previous 1, 2, or 5 years, were also investigated. These measures of health care utilization did not differ across sociodemographic groups with the exception of higher numbers of ED visits and charges in males than females (data not shown).

Discussion

This single-center study of a large spina bifida clinic highlights the significant medical demands placed on parent caregivers, patients, and the health care system as well as associations between health literacy, sociodemographic characteristics, and care compliance. Medicaid

Table 3. Emergency Department (ED) Visit and Charge Data of Study Cohort.

Variable	Overall (N = 105)
Total ED visits in last 1 year, n (%)	
0	53 (54.1)
1-2	27 (27.6)
3-4	14 (14.3)
>4	4 (4.1)
Total ED charges in last 1 year, n (%)	
0	53 (54.1)
1-1000	13 (13.3)
1001-10 000	19 (19.4)
>10 000	13 (13.3)
Total ED visits in last 2 years, n (%)	
0	36 (39.1)
1-2	26 (28.3)
3-4	14 (15.2)
>4	16 (17.4)
Total ED charges in last 2 years, n (%)	
0	36 (39.1)
1-1000	8 (8.7)
1001-10 000	28 (30.4)
>10 000	20 (21.7)
Total ED visits in last 5 years, n (%)	
0	23 (31.5)
1-2	12 (16.4)
3-4	10 (13.7)
5-6	10 (13.7)
>6	18 (24.7)
Total ED charges in last 5 years, n (%)	
0	23 (31.5)
1-5000	12 (16.4)
1001-10 000	9 (12.3)
10001-50 000	17 (23.3)
>50 000	12 (16.4)

insurance, lower parental education, and lower household income were associated with poor or marginal health literacy scores on NVS and BRIEF while Black or Hispanic race was associated with poor or marginal scores only on NVS. Parents whose children missed 4 or more catheterizations each week had lower NVS but not BRIEF scores. No significant associations were identified between UTI frequency, ED visits or charges, and health literacy. Excluding sex, ED visits and charges did not vary by sociodemographic characteristics. These results exemplify the complex relationships between sociodemographic characteristics, health literacy, medical compliance, disease complications, and health system utilization for a pediatric chronic disease.

Noncompliance in spina bifida has been shown to carry significant risk for morbidity and even mortality. Failure to properly manage bladder dysfunction

Table 4. Effect of Health Literacy on CIC Compliance.

Variable	NVS Score, Median (IQR)	P	BRIEF Score, Median (IQR)	P
How often each week catheterization missed		.03		.27
1-3 times	6 (4, 6)		19 (18, 20)	
4-6 times	1 (0, 2)		17.5 (15, 20)	
7 or more times	3.5 (2, 5)		19.5 (19, 20)	
Never	5 (4, 6)		18 (17, 20)	

Abbreviations: CIC, clean intermittent catheterization; NVS, Newest Vital Sign; IQR, interquartile range; BRIEF, Brief Health Literacy Screen.

can lead to recurrent UTI, hostile bladder pressures, and ultimately renal failure. In patients with augmentation cystoplasty, failure to catheterize can lead to bladder rupture with an estimated mortality rate of 23%.²³ In spinal cord injury patients on CIC, it has been shown that a lower frequency of catheterization, which causes the bladder to overdistend, increases the risk of UTI.^{24,25} In our cohort, a large percentage (46.9%) of parent caregivers reported that their child missed at least one catheterization over the previous week. This emphasizes the importance of targeted education that also addresses health literacy differences. This is underscored by evidence showing that deficiencies in compliance increase a patient's risk for development of disease-related comorbidities and overutilization of health care resources. Our results confirmed the high utilization of acute care known to exist in spina bifida patients, with 25% of eligible subjects in our cohort visiting the ED >6 times over 5 years and 16% incurring charges (ED visit(s) and associated hospitalization(s) if admitted) >\$50 000.

The interpretation of health disparities is often limited to racial or ethnic differences; however, in reality a more expansive definition is appropriate to describe disparities as they exist in the United States.²⁶ Relationships between sex, education, income, health insurance, non-English language, and health literacy also likely affect interactions with the health system and disease management. Lower education, low income, and ethnic/racial minority status have each been shown to predict worse health outcomes and inadequate health literacy.²⁷⁻³⁰ We found some of the same associations in our cohort, with Medicaid insurance status, lower parent education level, and lower household income predicting poor or marginal health literacy. Non-White race also predicted poor or marginal health literacy on NVS.

In previous studies in other chronic disease populations, lower health literacy has been shown to predict greater health system utilization and inadequate disease management.^{31,32} In this study, we identified poor

or marginal health literacy in up to 24.8% of parental caregivers by NVS screen, which approaches prior estimates suggesting 28.7% of parents in the United States fall below basic health literacy levels.³³ Interestingly, in our cohort, only 12.4% of parents scored poor or marginal on the BRIEF screen, which measures self-perceived health literacy. We find this result interesting as it suggests parents in our study population may overestimate their health literacy levels. Previous investigations comparing multiple health literacy screens have identified variability by sociodemographic factors, emphasizing the importance of recognizing the differences between instruments in the context of the population being studied and the need to consider the use of multiple instruments.²¹ Further investigation into the ideal health literacy screen for this patient population is necessary, and combination of multiple tools may be required until an optimal tool is identified.

In our cohort, we did find that poor or marginal health literacy on NVS screen was associated with worse compliance to CIC. This result emphasizes the concern that, as in other pediatric chronic disease models, parent caregiver health literacy negatively affects care compliance in spina bifida. One such pediatric chronic disease negatively affected is type 1 diabetes, where lower parent health literacy is associated with higher child HbA1c levels, representing inferior disease management and lower medication compliance.³²

Prior research on health system utilization in pediatric chronic diseases suggests that poor health literacy is associated with an increased number of ED visits and hospitalizations. Children with asthma who have parents with poor health literacy are more likely to utilize ED services, be hospitalized, and miss more days of school even after adjusting for asthma-related knowledge, medication use, and sociodemographic differences.³¹ Although we were able to identify an association between health literacy measured by NVS and CIC compliance, we did not identify any association between health literacy and hospital utilization as measured by ED visits or charges.

This study does have several limitations. Patients were recruited from a spina bifida clinic in Ohio that serves primarily White, English-speaking families. Also, non-primary English-speaking families were excluded, which further restricted the diversity in our population. Although this restriction only eliminated a small number of families, this may have introduced selection bias in comparison to the general population of pediatric patients with spina bifida in the United States. We acknowledge the need for a multi-institutional recruitment strategy in the future to provide a more generalizable sample, especially given the known associations between race/ethnicity and health literacy. Second, patients visiting our clinic are also very closely followed by a staff of nurses, social workers, case workers, nurse practitioners, and physicians, all of which meticulously monitor this captured population. This level of care likely differs significantly from that received by the general population of spina bifida patients in the community, potentially affecting the generalizability of our results. This selection bias, however, would be expected to underestimate any negative effects from poor health literacy and not undermine the clinical significance of our findings. Third, a single research assistant administered nearly all survey material to enrolled subjects in a standardized fashion, which could have introduced common-method variance. Fourth, it is also possible that families who feel they have poor or marginal health literacy may have declined to participate in the study due to fear of embarrassment. Although we did attempt to minimize this selection bias by using reassuring language during the recruitment process, it is likely some families did refuse enrollment for this concern. Also, although we were able to identify relationships between sociodemographic characteristics and health literacy and between health literacy and CIC compliance, no clinically significant predictors of health system utilization were identified. This may result from the selection bias encountered in our closely managed population, where despite the existence of known sociodemographic and health literacy risk factors, patient care was preserved due to our clinic model. It is also possible that due to the large geographic catchment of our clinic population some families choose to utilize local emergency health services, which were not captured in our analysis. An expansion of this study to other health care facilities may be necessary to better investigate more generalizable spina bifida outcomes.

Conclusion

This large, single-center study investigated sociodemographic characteristics, health literacy, UTI occurrence, CIC compliance, and ED utilization in children and

adolescent/young adults with spina bifida. Medicaid insurance, lower parent caregiver education level, and lower household income were associated with lower parent health literacy, and lower parent health literacy, as measured by NVS score, was associated with decreased compliance with CIC. No clinically significant associations were identified between sociodemographic characteristics or health literacy and UTI frequency or ED visits or charges. Poor or marginal health literacy however was identified by NVS screen in a quarter of our parental caregivers. This emphasizes the need to ensure all communication to families of children with spina bifida is comprehensible at all health literacy levels given the serious complications that can result from poor compliance in this patient population. Utilization of health literacy tools like teach-back may have an important role when educating families on interventions including CIC. Also, as expected, we did see high health care utilization overall in our cohort. Future research is necessary both contrasting our clinic patient population with community patient populations and determining how our model can be improved to accommodate families of all health literacy levels to ensure minimization of health disparities.

Author Contributions

JC: Contributed to conception and design; contributed to acquisition, analysis, and interpretation; drafted manuscript; critically revised manuscript; gave final approval; agrees to be accountable for all aspects of work ensuring integrity and accuracy.

DC: Contributed to conception and design; contributed to interpretation; drafted manuscript; critically revised manuscript; gave final approval; agrees to be accountable for all aspects of work ensuring integrity and accuracy.

DJM: Contributed to conception and design; contributed to acquisition, analysis, and interpretation; drafted manuscript; critically revised manuscript; gave final approval; agrees to be accountable for all aspects of work ensuring integrity and accuracy.

Declaration of Conflicting Interests

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