Interrelationships of sex, level of lesion, and transition outcomes among young adults with myelomeningocele

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ABBREVIATIONS

AMIS II	Adolescent Self-Management and Independence Scale II
LOL	Level of lesion
QOL	Quality of life

AIM To advance understanding of the interrelationships of sex, level of lesion (LOL), self-management, community integration (employment, independent living), and quality of life (QOL) in young adults with myelomeningocele.

METHOD A multicenter convenience sample of 50 individuals with myelomeningocele, 18 to 25 years of age (mean age 21y 5mo, SD 2y), participated in a structured clinical interview on self-management (Adolescent Self-Management and Independence Scale II [AMIS II]) and completed a self-report questionnaire comprising standardized measures. QOL was assessed using the World Health Organization Quality of Life (WHOQOL)-BREF instrument. A chart review yielded clinical data.

RESULTS Most participants were Caucasian (78%), female (56%: 28 females, 22 males), unemployed (58%), and in supervised living environments (74%). Eighty per cent had a history of hydrocephalus requiring shunt placement. A lumbar LOL was most frequently reported (64%), followed by a sacral LOL (22%), and thoracic LOL (7%). Males were more likely to report employment (p=0.008), but females had greater success in transitioning into independent living settings (p=0.015). LOL was a significant predictor of specific dimensions of self-management, employment, and QOL ($p < 0.05$). Mean scores on the AMIS II reflected deficits in condition management activities and tasks of everyday life. Limited QOL was also observed.

INTERPRETATION The overall low rates of employment and independent living suggest that individuals with myelomeningocele are experiencing great difficulty in achieving these milestones of emerging adulthood, regardless of sex. Limited success in developing self-management skills and restricted QOL also highlight vulnerability in this population.

Improved health interventions have increased the survival rate of young people born with myelomeningocele over the past three decades, with data suggesting the vast majority of affected individuals can be expected to survive long into adulthood.[1] Less progress has been made to support their psychosocial functioning as these individuals transition from adolescence into young adulthood.[2] However, a range of medical (e.g. muscle weakness and paralysis, bladder and bowel dysfunction, orthopedic abnormalities),[3] neurocognitive,[4] and social deficits present challenges to completing the developmental outcomes associated with early adulthood including self-management and community integration.[5] These health and social difficulties also place them at risk for psychological distress[6] and poor quality of life (QOL).[7] Consequently, young adulthood is regarded as a critical period of developmental change.[8]

For young adults with myelomeningocele, self-management of condition-specific tasks, such as medication ordering/administration and clean intermittent self-catheterization, as well as more general activities of daily living, are considered to be essential skills for community integration and have been associated with higher QOL ratings.[9] However, research suggests that independence in these tasks may be limited, particularly for individuals with hydrocephalus and a high level of lesion (LOL).[10] In their seminal study of adolescents and young adults with myelomeningocele, Blum et al.[11] observed a pattern of dependence on parents for condition management activities, especially bowel programs. A more recent descriptive study of 66 adolescents with myelomeningocele, 12 to 21 years of age, identified generally low participation in self-management activities.[12] The work of Davis et al.[13] further indicated that adolescents with myelomeningocele may be

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delayed in their development of autonomy skills by 2 to 5 years compared with age-matched peers.

Employment and independent living rates, key indicators of community integration, also suggest that this population is vulnerable. High levels of unemployment or underemployment and restricted experiences with independent living are regularly noted among young adults with myelomeningocele.[14–16] In contrast, research on QOL in adults with myelomeningocele has produced mixed findings (for a review, see Sawin and Bellin[17]). Although some investigations endorse a heightened risk for poor overall and domain-specific dimensions of QOL in individuals with myelomeningocele compared with peer groups,[16,18] other studies revealed moderate to high levels of satisfaction with QOL in adolescents and young adults with myelomeningocele (see, for example, Leger[19]) or found QOL scores within the average range.[20]

Young females with myelomeningocele may be especially vulnerable to poor psychosocial outcomes owing to their double jeopardy status related to sex and disability.[21,22] Females with physical disabilities are particularly at risk for material hardship,[23] social difficulties,[24] and experiences of sexual exploitation and abuse.[25] Furthermore, compared with their male counterparts, females with myelomeningocele have reported lower rates of employment[26,27] and decreased QOL.[28] However, until now, no study has examined sex differences in transition outcomes across multiple domains of health management and psychosocial functioning. Research on transition outcomes among young adults with myelomeningocele in the USA is particularly restricted in scope. Guided by the bio-neuropsychosocial model of psychosocial adjustment in emerging adults with myelomeningocele,[29] this study aims to advance understanding of the interrelationships of sex, LOL, and transition outcomes in young adults with myelomeningocele. Our intent was to evaluate central variables that fall under the 'activities and participation' domain of the World Health Organization's International Classification of Functioning, Disability and Health framework[30] (e.g. self-management, employment, and independent living) as well as the overarching variable QOL. The primary hypotheses tested in this research were as follows: (1) after controlling for the effects of LOL, young males with myelomeningocele would report higher rates of self-management, community integration (employment, independent living), and QOL than young females; (2) self-management would be significantly associated with community integration and QOL.

METHOD

Participants were part of a larger longitudinal investigation of psychosocial adaptation in young adults with myelomeningocele.[6] The data reported here focus on select transition outcomes (self-management, community integration, QOL) in a subset of 50 young adults with myelomeningocele recruited from five geographically diverse multidisciplinary specialty clinic sites in the USA.* Study eligibility criteria included the following: (1) primary diagnosis of myelomeningocele, (2) 18 to 25 years of age, (3) residence in catchment areas of participating sites, and (4) capacity to understand study instruments. An adapted version of the MacArthur Competence Assessment Tool[31] was administered to all eligible participants to assess for the capacity to provide informed consent. Responses to five questions exploring the participant's understanding of the purpose of the project, activities involved in study participation, benefits of participation, risks and discomforts associated with participation, and procedure to withdraw from the study were scored on a range of 0–2 (0, inadequate understanding; 1, partial understanding; 2, adequate understanding). To be enrolled in the study, participants must have received a total score of 8 or higher, out of a possible score of 10, on the measure. As described in Bellin et al.,[6] of the 168 eligible individuals who received medical services at the study sites, 64 (38%) agreed to participate. Three individuals failed the competence screening and 11 had a primary diagnosis other than myelomeningocele (e.g. meningocele, spina bifida unspecified), resulting in a final sample of 50 young adults with myelomeningocele.

What this paper adds

- Young adults with myelomeningocele require ongoing assistance in condition-specific management activities and general activities of daily living.
- Employment and independent living rates among young adults with myelomeningocele differ by sex.
- Level of lesion is significantly associated with aspects of self-management, community integration, and quality of life.

Procedure

Following approval by the associated institutional review boards and the Professional Advisory Council of the Spina Bifida Association, participants were recruited through a mailed letter of invitation and by face-to-face contact during routine visits to a myelomeningocele clinic. Once informed consent was obtained, participants completed a structured clinical interview on self-management and responded to a self-report questionnaire including study measures described below. Participants received a US$35.00 gift-card as an acknowledgment of their time. Chart reviews were performed by study staff to obtain clinical data including LOL, previous medical procedures and other medical diagnoses, and height and weight. De-identified study materials were sent to the project principal investigator (MHB) for data management and analysis.

Measures

Self-management

Participants were administered the Adolescent Self-Management and Independence Scale II (AMIS II) as an index of self-management.[32] The AMIS II is a structured clinical interview that gathers information about participant knowledge and behaviors in myelomeningocele management activities and general activities of daily living. Participant descriptions of their activities in these domains are rated on a seven-point response category (1, total assistance, to 7,

*No differences in key demographics or study measures were found by study site, so participants were combined for the analysis.

Table I: Descriptive analysis of self-management and quality of life measures in young adults with myelomeningocele (n=50)

	Mean	SD	Range	Number of items	α
Self-management[31]					
Self-management (full scale)	4.52	1.47	1–7	17	0.93
Self-management: condition factor	4.89	1.41	1–7	7	0.86
Self-management: independent living skills factor	4.27	1.64	1–7	10	0.90
Quality of life[33]					
Physical health domain	69.14 (77.10)	18.81 (11.6)	6–100	7	0.78
Psychological domain	65.38 (75.10)	13.97 (10.7)	25–94	6	0.69
Social relationships domain	65.86 (71.7)	19.61 (14.4)	19–100	3	0.62
Environmental domain	72.76 (71.7)	13.68 (11.5)	50–100	8	0.67

The raw quality of life domain scores were transformed to a 0–100 scale according to the scoring guidelines outlined in the World Health Organization Quality of Life (WHOQOL)-BREF manual to allow comparison with normative data, which are presented in parentheses.

complete independence) by study staff. Confirmatory factor analysis supports two factors: (1) self-management: condition factor (seven items; e.g. managing medication for myelomeningocele, knowledge of myelomeningocele, complication prevention, personal safety, advocacy, accessibility, and family involvement in managing myelomeningocele); (2) self-management: independent living skills factor (10 items; e.g. managing money, transportation, making money, community living skills, ordering supplies, managing insurance, household skills, healthcare appointments, social communication, and general problem solving). The measure also includes a second-order overall self-management factor.[32] The statistics support a good fit of the data to this model (reliabilities ranged from r=0.72–0.89).[32] Similar to the process used for other national functional assessment tools, interrater reliability for this study was established by written scoring of case studies constructed by one of the AMIS II developers (Sawin). Each data collector established interrater reliability greater than r=0.90 with standard case scoring on two cases before beginning data collection. Good internal reliability for the AMIS II was found in this sample (Table I).

Community integration

Employment status and independent living were used as two indicators of community integration.[33] Employment was dichotomized as 0 (unemployed) or 1 (employed). Self-report of living status was operationalized as 0 (residence in a supervised living environment, e.g. at home with parent/guardian, assisted living facility) or 1 (independent living).

QOL

The 26-item World Health Organization Quality of Life (WHOQOL)-BREF instrument provided an assessment of four related domains of QOL: physical health (seven items), psychological (six items), social relationships (three items), and environment (eight items).[34] Items range from a low of 1 to a high of 5, with higher scores reflecting greater levels of perceived QOL. Analyses of internal consistency, discriminant validity, and construct validity suggest the WHOQOL-BREF is a psychometrically strong measure of QOL.[35] Cronbach's alpha ranged from 0.62 (social relationships) to 0.78 (physical health) in this research (Table I). The measure has been used internationally to research subjective QOL in individuals with myelomeningocele.[36]

Statistical analysis

SPSS 18.0 (SPSS Inc, Chicago, IL, USA) was used to compute statistical analyses (two-tailed tests, α=0.05). A multivariate analysis of variance was run to evaluate differences on the AMIS II condition and independent living factors by sex (1, male; 2, female) and LOL (1, sacral; 2, lumbar; 3, thoracic). Next, separate hierarchical binomial logistic regression analyses were run to model the employment and independent living outcome measures using sex and self-management (total AMIS II score) after controlling for LOL. In the final analysis, a multivariate analysis of covariance was run to assess group differences on the combined set of QOL domains by sex, LOL, self-management (total AMIS II score as a fixed factor), employment status, and independent living. The assumptions of homogeneity of variance and normal distribution were explored and met for the multivariate analyses of variance and covariance.

RESULTS

Participants reported a mean age of 21 years 5 months (SD 2y), range 18 to 25 years. Most were Caucasian (78%) and female (56%), and most had a history of hydrocephalus requiring shunt placement (80%). The mean number of surgical revisions to the shunt was 3.03 (SD 2.73). A lumbar LOL was most frequently reported in the medical chart (64%), followed by a sacral LOL (22%), and thoracic LOL (7%). Half of the cohort reported earning a high-school degree or General Education Diploma (51%), and several had completed college (8%) or were current college students (10%). Fifty-eight per cent of all participants were unemployed, and those who were gainfully employed generally held low-wage, entry-level customer service positions such as a store greeter or grocery clerk. Most participants reported residence in a supervised environment (74%, e.g. at home with parents/guardians, group home). Eleven of the 12 individuals living in independent settings were females.

Self-management model[a]

No differences in self-report of self-management skills were observed when participants were grouped according to sex, but a significant finding was found for LOL (Roy's largest root=0.23, $F_{(2,46)}$=5.34, p=0.008). Specifically, significant differences were observed on the self-management: condition factor ($F_{(2,46)}$=5.29, p=0.009). Post-hoc tests using Tukey's procedure, a preferred analysis for controlling inflated type I error rates when homogeneity of variance is met,[37] indicated higher scores for individuals with a sacral LOL (mean 5.81) compared with those with a thoracic LOL (mean 3.78; p<0.05).

Community integration: employment model

Level of lesion using thoracic LOL as the reference category was entered on the first step of the model and resulted in a significant improvement in classification of employment status, from 58% to 70% (χ^2=7.55, p=0.02). Sex and self-management were entered in the second step and also resulted in a significant increase in correct prediction of being employed (57–67%, χ^2=12.25, p=0.02). Good model fit was indicated by moderate to large pseudo-R^2 values (Cox and Snell=0.33, Nagelkerke=0.44). In the final model, significant parameter estimates were obtained for sex and LOL (Table II). On average, the odds of being employed changed by a factor of 0.05 when comparing females with males. A significant effect was found between lumbar and both thoracic and sacral LOL. The odds of gainful employment changed by a factor of 0.06 when comparing lumbar LOL with thoracic LOL and by 0.04 when comparing sacral LOL with lumbar LOL.

Community integration: independent living model

Inclusion of LOL in the first step of the independent living model again resulted in a significant increase in correct classification of unsupervised community residence, from 75 to 80% (χ^2=8.60, p=0.01). Sex and self-management were entered in the second step and similarly improved classification of independent living status (80–94%, χ^2=19.31, p<0.001). Large pseudo-R^2 values (Cox and Snell=0.43, Nagelkerke=0.65) suggested a good model fit. In the final model, significant parameter estimates were observed for sex and self-management (Table III). Specifically, the odds of living independently in the community changed by a factor of 34.26 when comparing females with males. Additionally, a unit increase in self-management changed the odds of independent living by a factor of 4.03.

QOL model

No significant differences in self-report of QOL domains were observed when participants were evaluated by sex, self-management, employment status, or independent living. However, a significant multivariate result was observed for LOL (Roy's largest root=0.32, $F_{(4,40)}$=3.18, p=0.02). A series of one-way analyses of variance revealed differences on the social relationships domain only ($F_{(2,42)}$=5.94, p=0.005). Post-hoc tests using Bonferroni's adjustment indicated significantly higher scores for individuals with a sacral (M=4.23, p=0.02) or thoracic LOL (M=4.20, p=0.03) than those with a lumbar LOL (M=3.37).

[a]All models were also run with hydrocephalus as a covariate. Because hydrocephalus was non-significant and model results did not change, the parsimonious model with LOL only is presented.

Table II: Logistic regression model for predicting employment status

Predictor	*B*	SEB	Wald	df	*p*	Exp(*B*)	95% CI
Sacral LOL[a]	0.53	1.21	0.19	1	0.66	1.79	0.16–18.11
Lumbar LOL[a]	−2.83	1.32	4.62	1	0.032	0.06	0.004–0.78
Lumbar LOL[b]	−3.36	1.24	7.32	1	0.007	0.04	0.003–0.40
Sex	−2.92	1.11	6.93	1	0.008	0.05	0.006–0.47
Self-management	0.18	0.25	0.53	1	0.47	1.20	0.73–1.97
Constant	1.96	1.55	1.63	1	0.20	7.20	
Model evaluation			χ^2				
Likelihood ratio test			19.81	4	0.001		
Pseudo-R^2							
Cox and Snell			0.33				
Nagelkerke			0.44				

Separate regression models were run with thoracic level of lesion (LOL) and sacral LOL as the reference group respectively. [a]Compared with thoracic LOL. [b]Compared with sacral LOL. df, degrees of freedom; 95% CI, 95% confidence interval.

Table III: Logistic regression model for predicting independent living

Predictor	*B*	SEB	Wald	df	*p*	Exp(*B*)	95% CI
Sacral LOL[a]	−0.07	1.62	0.001	1	0.97	0.945	0.004–1.73
Lumbar LOL[a]	−2.44	1.53	2.56	1	0.11	0.09	0.04–22.60
Lumbar LOL[b]	−2.39	1.26	3.59	1	0.06	0.09	0.008–1.084
Sex	3.53	1.46	5.86	1	0.015	34.28	1.96–599.27
Self-management	1.40	0.55	6.37	1	0.012	4.03	1.37–11.92
Constant	−9.34	3.24	8.30	1	0.004	0.000	
Model evaluation			χ^2				
Likelihood ratio test			27.91	4	<0.001		
Pseudo-R^2							
Cox and Snell			0.43				
Nagelkerke			0.65				

Separate regression models were run with thoracic level of lesion (LOL) and sacral LOL as the reference group, respectively. [a]Compared with thoracic LOL. [b]Compared with sacral LOL. df, degrees of freedom; 95% CI, 95% confidence interval.

DISCUSSION

The aim of this research was to expand understanding of the associations between sex, LOL, self-management, community integration, and QOL in a sample of young adults with myelomeningocele residing in the USA. A major finding relates to the observed sex differences in the extent to which this population has integrated into the community. Males were more likely to report employment, but females had greater success in transitioning into independent living. Although the employment-related findings were expected based upon past research,[26,27] the findings involving independent living status

were not. Interestingly, sex was a strong predictor of independent living situation, even though there were no sex-based differences in self-management skills. Given the limited resources available to support individuals transitioning into young adulthood, it may be necessary to direct funding towards employment training or preparation for independent living, rather than both areas simultaneously. In this respect, we propose that sex may be an important factor in the resource allocation process with this population.

The results of this study further elucidate the reduced functioning within the 'activities and participation' domain of the World Health Organization's International Classification of Functioning, Disability and Health.[30] The employment (42%) and independent living (24%) rates are consistent with a previous longitudinal study of young adults with myelomeningocele living in the USA,[1] are lower than was reported for other populations with health conditions,[38] and suggest that young adults with myelomeningocele continue to experience significant difficulty regardless of sex. Although we did not systematically explore whether our participants were actively pursuing community integration, qualitative data collected at one of our participating sites suggest many are indeed seeking employment without success. In comparison, 2009 employment rates suggest that 62.2% of young adults aged 20 to 24 years in the USA are in the labor force.[39] Limited success in developing self-management skills and restricted QOL also highlight vulnerability in this group. Specifically, the scores on the condition and community living skills factors of the AMIS II reflect the need for ongoing assistance and prompting in the management of myelomeningocele, as well as activities of daily living. QOL scores on three of the four WHOQOL-BREF domains were lower than has been reported for individuals without a health condition, suggesting that this population is also at risk for reduced QOL.

Observed relationships between self-management and the indicators of community integration also warrant attention. Consistent with previous reports of the central role that independence in daily life activities plays in one's capacity for community living,[10] self-management was a significant predictor of living situation. Participants who reported greater self-management skills were more likely to have current residence in unsupervised settings. In contrast, no association was found between employment and self-management skills. Although a basic level of condition management may be necessary to obtain and maintain employment, data from the current study do not suggest a central role of condition self-management in the longstanding pattern of underemployment of young adults with myelomeningocele. Anecdotal reports from our research participants suggested several alternative factors that may be useful for investigating employment barriers in the future, including limited or unreliable transportation options, income restrictions imposed as a condition of medical insurance eligibility, and underdevelopment of specific job skills.

Other noteworthy findings pertain to the associations between LOL and transition outcomes. Because LOL is used as marker of severity, with a higher LOL associated with more impairment,[7] it is not surprising that individuals with a sacral LOL had a higher rate of employment than those with a lumbar LOL. We also found that individuals with a sacral LOL reported greater skills in managing condition-specific tasks (e.g. medication ordering) than those with a thoracic LOL. These findings parallel previous results indicating an inverse relationship between LOL and independence.[10] Interestingly, differences in QOL by LOL were also found whereby individuals with a sacral or thoracic LOL reported higher social relationships domain scores than those with a lumbar LOL. This last finding is intriguing as it does not support a simple linear association between QOL and LOL. The relationship may in part be explained by the marginality hypothesis,[40] which suggests individuals with more mild disability have poorer psychosocial outcomes because fitting in with peers, both typically developing and those with more profound disability, can prove to be challenging and possibly lead to reduced QOL. Because our previous work revealed high rates of anxiety and depressive symptoms in this population,[6] further inquiry into the factors impacting on QOL is warranted, particularly if potentially modifiable influences can be identified for treatment purposes (e.g. coping skills and negative cognitions). Differences in QOL by mobility status have also been identified in this population, with full-time wheelchair users endorsing especially low QOL,[41] so examining modifiable factors in the environment (e.g. barriers to accessibility) likewise seems important.

Study limitations and future directions

Study findings were limited by our sample size, which restricted the number of variables entering the models and the type of analyses run. Given the broad age range and differing levels of education reported for participants, we conducted preliminary bivariate analyses to explore associations among these important demographics and the transition variables. No significant relationship was found. To maximize our power we did not include these variables as covariates in the final models. Other methodological limitations relate to the cross-sectional nature of the data and our reliance on self-report measures, which prevent us from ruling out common method variance as an explanation for significant findings.[42] The recruitment of participants from multidisciplinary clinics is also noteworthy. Individuals with myelomeningocele who receive care at these sites may differ from those who access health services from less specialized settings, thus limiting the generalizability of our findings. However, the demographic (e.g. education level, employment, and independent living rates) and clinical (LOL, shunt status) characteristics of our sample resemble what has been reported in other studies with young adults living with myelomeningocele.[1,20,43] Lastly, future research would benefit from including other disability groups to ascertain whether individuals with myelomeningocele are especially vulnerable to poor psychosocial outcomes owing to the complexity of this condition. Despite these limitations, our findings offer useful insights to the challenges individuals with myelomeningocele in the USA may encounter as they transition into young adulthood and highlight the need for increased attention on psychosocial aspects of this condition.

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