

Self-management, preventable conditions and assessment of care among young adults with myelomeningocele

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Abstract

Aim In this multicentre cross-sectional study we aimed to identify whether self-management ability and healthcare service delivery factors were related to preventable conditions [urinary tract infections (UTIs), pressure ulcers] and healthcare utilization [emergency room (ER) visits, hospitalizations] specifically in a sample of young adults with myelomeningocele.

Background Spina bifida is one of the most common congenital birth defects, affecting over 166 000 individuals living in the USA. Participants completed a questionnaire comprised of a self-report measure of healthcare services (Patient Assessment of Chronic Illness Care), recent healthcare utilization and preventable medical conditions. A structured clinical interview [Adolescent Self-Management and Independence Scale 2 (AMIS)] was administered to assess self-management. Multiple linear regression models were run to explore individual and combined effects of the AMIS, Patient Assessment of Chronic Illness Care, condition severity variables (shunted hydrocephalus, lesion level) and demographic factors in explaining variability in ER visits, hospitalizations, UTIs and pressure ulcers.

Results Higher number of UTIs were associated with no history of shunting, lower educational levels, higher employment levels and lower AMIS scores (adjusted $R^2 = 0.774$, $P = 0.002$). Higher number of ulcers was associated with higher motor level and higher educational level (adjusted $R^2 = 0.378$, $P = 0.017$). Higher number of hospitalizations was associated with higher number of wounds and lower AMIS scores (adjusted $R^2 = 0.544$, $P = 0.012$). A significant model for ER visits was not identified.

Conclusions Initiatives aimed at improving self-management skills or providing support for skin and bladder care may be warranted for those with high levels of motor impairment or lower educational levels. Better detection of wounds may be seen in those with higher employment levels. Spina bifida is a complex condition, but one whose most prevalent concomitant secondary conditions may be preventable through simple measures that improve self-management and through health educational initiatives targeted to specific patient groups.

Keywords

assessment of healthcare needs, myelomeningocele, pressure ulcers, prevention and control, self-care, urinary tract infections

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Introduction

Spina bifida (SB) results from failure of the neural tube to close during embryonic development. SB is one of the most common

congenital birth defects with a prevalence of over 166 000 Americans. Approximately eight per thousand births are affected by SB or a similar neural tube defect. Myelomeningocele (MM), a severe form of SB, affects one in 800 infants (Spina

Bifida Association 2010). MM is a complex condition, often associated with hydrocephalus, neurogenic bladder, sensory loss and paralysis, which can lead to other secondary medical conditions (Verhoef *et al.* 2004). Many individuals with MM are living well into adulthood because of significant advances in medicine and rehabilitation (Hunt 1999). However, individuals with shunting for hydrocephalus and a spinal lesion level above L2 have been found to be less independent for mobility and personal care (Verhoef *et al.* 2006).

Two of the most common conditions associated with MM are urinary tract infections (UTIs) and various types of wounds, including pressure ulcers, many cases of which are thought to be preventable (Kinsman & Doehring 1996). Kinsman and Doehring (1996) showed that individuals with MM are hospitalized on average three to four times per year. Our prior work showed that 37.7% of hospitalizations of young adults with MM age 18–35 are a result of potentially preventable conditions including UTIs and several types of wounds (Dicianno & Wilson 2010). About 1% of these hospitalizations result in death. Each stay had a mean length of stay of 7.1 days and cost in excess of \$30 000. The average length of stay, cost per stay and percentage of all stays due to preventable conditions were highest in the youngest cohort of patients. However, the connection among impaired self-management and preventable conditions or unplanned hospital utilization in young adults with MM has not yet been fully examined.

The Chronic Care Model (CCM) provides a framework of care that is patient-centred, proactive, and focuses on planning and creating shared goals to optimize health and psychosocial functioning. It also emphasizes comprehensive follow up with patients, open communication and shared decision-making (Glasgow *et al.* 2005a). Research conducted within other chronic healthcare populations, such as diabetes, heart disease and asthma, has shown important associations between the receipt of care services based on CCM principles and positive health outcomes (Glasgow *et al.* 2005a). The link between CCM and preventable conditions or unplanned hospital utilization in patients with MM has not been evaluated.

In this paper, we aimed to advance understanding of the relationships among self-management, patient assessment of healthcare services, preventable conditions and healthcare utilization. We hypothesized that lower self-management scores and lower patient assessments of care within the CCM are significantly associated with UTIs and pressure ulcers in a sample of young adults with MM. We also hypothesized that lower self-management scores, lower assessments of care received, number of UTIs and number of pressure ulcers are significant contributors to emergency room (ER) visits and hospitalizations.

Methods

This study was part of a multisite, longitudinal study examining a range of medical and psychosocial outcomes among young adults living with MM (Dicianno *et al.* 2009; Bellin *et al.* 2010, Bellin *et al.* 2011). This study was approved by the University of Pittsburgh Institutional Review Board and the IRB at each respective institution. We recruited subjects between ages 18 and 25 with a primary diagnosis of MM who received care from five multidisciplinary SB clinics around the USA. To ensure participants understood the informed consent process, an Evaluation to Sign Consent Form adapted from the MacArthur Competence Assessment Tool (Appelbaum & Grisso 2001) was administered after the participant reviewed the combined informed consent/HIPAA document. Participants responded to questions about the study methodology, potential risks/benefits and withdrawal procedures. Individuals who scored 8 or more out of 10 on this screening tool were enrolled in the study. See Bellin and colleagues (2010) for more detailed information on sample recruitment and screening. A total of 64 individuals expressed interest in participating. Three subjects failed competence screening, and 61 subjects were subsequently enrolled in the multicentre study. In order to obtain a uniform cohort of patients, we then limited our analysis to individuals with a diagnosis of MM and used the most recent data collected (from Year 2 of the study). Out of the initial cohort enrolled, a total of 38 subjects met criteria for inclusion.

Participants completed a self-administered questionnaire packet via in-person interview or by telephone. The questionnaire packet included general demographic questions, recent medical information (e.g. UTI, pressure ulcers in the last 3 years) and healthcare usage (e.g. ER visits in the last 12 months, hospitalizations in the last 3 years) data. Subjects were also asked to rate their average pain level in the prior week on a scale from 1 to 10.

A structured clinical interview on participant self-management activities was also conducted by trained investigators. The Adolescent Self-Management and Independence Scale 2 (AMIS) (Hesbacher *et al.* 1980) examined participant knowledge and behaviour in MM specific and general activities of daily living, including personal safety, condition knowledge, medication management, money management, transportation, household skills and community living skills. A chart review was also conducted to obtain insurance information and to collect select clinical information, such as neurosurgery history, recent surgeries and the patient's motor level. Motor level was categorized as sacral (intact plantar flexion), low lumbar (intact knee flexion), mid lumbar (intact knee extension), high lumbar

(intact hip flexion) and thoracic (no movement of legs) based on the patients' physical examination.

Patients completed the Patient Assessment of Chronic Illness Care (PACIC) to measure the receipt of CCM services (Glasgow *et al.* 2005b). Participants were asked to rate the facets of health services on a 5-point scale with higher scores reflecting compliance with the principles of the CCM. The PACIC has documented reliability ($\alpha = 0.96$) and concurrent and construct validity, and has been established for use in a range of chronic conditions (Glasgow *et al.* 2005b).

Significance levels were set at 0.05 a priori. SPSS version 13 was used to test four regression models using statistical backward sequential analysis. Models 1 and 2 used the dependent variables of UTIs requiring antibiotics and pressure ulcers in the last 3 years respectively. These dependent variables were normalized using Poisson normalized values. Independent variables for the models included demographic information (age and gender), factors that may cause disparity in health outcomes (employment level, education level, insurance type), factors that are known to impact self-management skills and health (motor level of spinal lesion, history of shunted hydrocephalus, and pain), and the variables of interest, PACIC and AMIS total. Variables were sequentially removed until model fit was maximized and were also removed when independent variables were co-linear. Models 3 and 4 used the dependent variables ER visits in the last 12 months and hospitalizations in the last 3 years, respectively, with Poisson normalization. The same method was used except that UTIs and ulcers were also included in the models as independent variables. The responses to individual questions within the PACIC were also expressed as median and ranges.

Results

Table 1 shows general demographics of the participants. Five (13.2%) were African-American, two (5.3%) were Hispanic, one participant (2.6%) categorized himself/herself as 'other' or more than one ethnicity, and the rest (78.9%) were Caucasian.

Table 1. Overall demographics

<i>n</i>	38
Mean age (SD)	22.2 \pm 2.0 years
Number female (%)	20 (52.6)
Number with shunted hydrocephalus (%)	32 (84.2)
Median pain level (range)	3 (1–10)
Mean PACIC (SD)	72.5 \pm 13.1
Mean AMIS total (SD)	83.4 \pm 18.0

AMIS, Adolescent Self-Management and Independence Scale 2; PACIC, Patient Assessment of Chronic Illness Care.

The distribution of motor levels was as follows: 7 (18.4%) sacral, 7 (18.4%) low lumbar, 6 (15.8%) mid lumbar, 11 (28.9%) high lumbar and 6 (15.8%) thoracic level lesions.

Three subjects (7.9%) were in high school, 19 (50.0%) had received a high school diploma, 2 (5.3%) had enrolled in vocational schools, 9 (23.7%) had enrolled in college, 2 (5.3%) had received a college degree and 2 (5.3%) had enrolled in various other certificate programmes. Seventeen (44.7%) were unemployed, 16 (42.1%) were employed part-time and four (10.5%) were employed full-time. Subjects carried a wide variety of insurances, most commonly Medicare (15, 39.5%).

The overall median and range for the occurrence of each medical outcome variable were as follows: UTI 2 (0–20) in the last 3 years, pressure ulcers 0 (0–5) in the last year, ER visits 0 (0–3) in the last year and hospitalizations 0 (0–20) in the last 3 years.

In the regression model using UTI as the dependent variable (adjusted $R^2 = 0.774$, $P = 0.002$), UTIs were significantly associated with no history of shunting ($P = 0.004$, $t = -3.814$), lower education level ($P = 0.010$, $t = -3.227$), lower AMIS scores ($P = 0.034$, $t = -2.500$) and higher employment level ($P = 0.029$, $t = 2.593$).

In the regression model using pressure ulcers as the dependent variable (adjusted $R^2 = 0.378$, $P = 0.017$), pressure ulcers were significantly associated with higher education level ($P = 0.031$, $t = 2.372$) and higher motor level ($P = 0.035$, $t = 2.325$).

In the regression model using hospitalizations as the dependent variable (adjusted $R^2 = 0.544$, $P = 0.012$), hospitalizations were significantly associated with lower AMIS scores ($P = 0.045$, $t = -2.242$) and higher number of ulcers ($P = 0.013$, $t = 2.903$).

No significant regression model could be constructed for ER visits as the dependent variable.

Table 2 shows median scores and ranges for each question on the PACIC. The lowest median score (1) was seen in the subset 'Encouraged me to go to a specific group or class to help me cope with SB'.

Discussion

As hypothesized, AMIS scores were negatively associated with number of UTIs. Clinical practice guidelines for UTI prevention programmes stress frequent clean intermittent catheterization and infection control measures, all which require significant effort and follow up from the patient (Paralyzed Veterans of America 2010). We are aware of no other studies that have made the direct correlation between self-management and UTI in MM. Moreover, the fit of our model was excellent, with over

Table 2. Results of the PACIC

PACIC subset	Median	Range
Asked for my ideas when we made a treatment plan	4	1–5
Given choices about treatment to think about	4	2–5
Asked to talk about any problems with meds or effects	4	3–5
Given a written list of things I should do to improve my health	3.5	1–5
Satisfied that my care was well organized	4	1–5
Shown how what I did to take care of myself influenced SB	4	1–5
Asked to talk about my goals in caring for SB	3.5	1–5
Helped to set specific goals to improve my eating or exercise	4	1–5
Given a copy of my treatment plan	4.5	1–5
Encouraged me to go to a specific group or class to help me cope with SB	1	1–5
Asked questions either directly or on a survey about my health habits	4	1–5
Sure that my doctor or nurse thought about my values, beliefs and traditions when they recommended treatments to me	4	2–5
Helped to make a treatment plan that I could carry out in daily life	4	2–5
Helped to plan ahead so I could take care of SB even in hard times	4	2–5
Asks how SB affects my life	3	2–5
Contacted after a visit to see how things were going	3	1–5
Encouraged to attend programmes in the community that could help me	3	1–5
Referred to dietician, health educator or counsellor	2.5	1–5
Told how my visits with other types of doctors, like an eye doctor or surgeon, helped my treatment	3	1–5
Asked how my visits with other doctors were going	4	1–5

PACIC, Patient Assessment of Chronic Illness Care; SB, spina bifida.

75% of the variance explained. Lower educational level also contributed to more UTIs, which may indicate the need for more initiatives for health education in these populations. Alternatively, recurrent UTIs may also impact an individual's ability to stay in school. Surprisingly, those with no history of shunted hydrocephalus and higher employment level had more UTIs. This seemingly contradictory finding may be due to those with higher cognitive or levels being able to recognize and seek treatment for UTIs more readily, or a limitation of sampling error due to the low number of individuals without shunts and employed full-time in this study.

Higher educational level was associated with more ulcers. Again, one explanation is that the ulcers reported in the study were detected more readily by those with higher educational level or, alternatively, that care was more readily sought. As successful prevention of skin breakdown requires not only daily self-management with patient- or caregiver-initiated skin checks but also regular physician follow ups, nutrition

intervention, physician management of urinary or fecal incontinence, and positioning and seating interventions, improved skin integrity may also depend heavily on the preventative measures provided by the multidisciplinary care team. Number of pressure ulcers was associated with motor level, with higher levels being associated with more ulcers. Intuitively, those who are likely more limited in ability to weight shift due to higher lesion levels seem to develop more ulcers. Unfortunately, sensory level was not a variable that was collected as part of the larger study and could not be examined.

A major finding of our work relates to the significant associations between preventable conditions and healthcare usage. Number of pressure ulcers was strongly associated with number of hospitalizations, with more ulcers being associated with more hospitalizations. In addition, self-management score was also associated with hospitalizations, with lower scores associated with more hospitalizations. We cannot assume causality, as ulcers and problems with self-management can certainly occur in individuals who are hospitalized often because of their many comorbid conditions. Data on the specific diagnoses responsible for each admission or ER visit in this study were not available. However, our prior work (Dicianno & Wilson 2010) shows that ulcers are indeed a frequent reason for hospitalization of individuals with SB and that many of these hospitalizations are potentially preventable. We were not able to build a regression model for ER visits. More research is needed to more clearly delineate reasons for ER admissions those with SB and whether these ER visits result in subsequent hospitalizations.

In our prior work, we showed that hospital admission rates in young adults with SB in the USA aged 18–35 are actually higher than those of other age groups for preventable conditions such as ulcers and UTIs (Dicianno & Wilson 2010). The low median frequency of medical outcomes seen in this study may be explained by patients receiving adequate education or preventive care in their multidisciplinary clinics. Moreover, even though many of the subjects in this study received care in urban teaching hospitals, hospitalization rates due to ulcers and UTIs in SB have not been found to be related to the type of hospital where care is received (Dicianno & Wilson 2010).

Based on PACIC results, outpatient clinics treating patients with SB may be able to improve care delivered by promoting small groups, classes and workshops that educate patients on preventable conditions. Contrary to our hypotheses, total PACIC score was not a significant predictor in any of the models. Because relatively high median scores were reported for most categories in the PACIC, a ceiling effect may have had an effect on the outcomes. More work is certainly needed to investigate the impact of the CCM in other models of care.

Study findings are limited by several methodological considerations. Causality of observed relationships cannot be determined because of the cross-sectional nature of the data. The external validity of this study may also be limited as our sample was comprised of patients who attend multidisciplinary clinics; however, as mentioned above, our prior work has revealed that stratification of data by hospital type seems to have an effect only on admission rates because of shunt failure. Finally, the sample chosen may function at a higher cognitive level than other cohorts as those who were not able to give informed consent were screened out.

Spina bifida is a complex condition, but one whose most prevalent concomitant secondary conditions may be preventable through simple measures that improve self-management and through educational initiatives targeted to specific patient groups.

Key messages

- Improving self-management scores may decrease the incidence of preventable conditions in patients with spina bifida.
- Educational initiatives based on the Chronic Care Model targeted towards specific patient groups may help decrease the incidence of preventable conditions.

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