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ORIGINAL PAPER

Impact of Spina Bifida on Parental Caregivers: Findings from a Survey of Arkansas Families

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Abstract The well-being of caregivers of children with spina bifida and other conditions is an important topic. We interviewed the primary caregivers of 98 children aged 0–17 years with spina bifida sampled from a population-based birth defects registry in Arkansas and the caregivers of 49 unaffected children. Measures of caregiver well-being were compared between the groups and by level of lesion (sacral, lower lumbar, and upper lumbar/thoracic). We performed linear and logistic regression analysis to test the associations controlling for other characteristics. Among caregivers of children with spina bifida, the average number of hours of sleep was significantly less than reported by other caregivers and was associated with lesion level among children less than 7 years of age. Significant associations, often varying by child age, were also found for the caregiver's reports of lower Quality of Well-Being (QWB) score, often feeling blue, rarely feeling happy, fair or poor health, lack of leisure days, and not hosting friends, but no significant association was found with not visiting friends. The intensive long-term care required by children with spina bifida, particularly by those with higher lesions, can negatively impact caregiver health and well-being. Support for these caregivers is needed.

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Introduction

Spina bifida aperta is a neural tube defect characterized by the incomplete closure during fetal development of the vertebral bones and surrounding skin, resulting in a protrusion of the spinal cord (Oppenheimer 2008). A child's neurological dysfunction generally occurs from the level of the lesion on downward, although a great deal of variability exists (Walker and Peterson 2008). There are four main lesion levels: (1) cervical, which affects the nerves in the neck; (2) thoracic, which affects the nerves in the upper torso downward; (3) lumbar, which affects the nerves in the lower torso downward; and (4) sacral, which affects the nerves at the very bottom of the spine (Walker and Peterson 2008). Lesion level has been associated with survival and impairments, most frequently in sphincter control (Preis et al. 2005; Verhoef et al. 2006). In particular, most individuals with low lesion levels are ambulatory whereas most of those with higher level lesions do not walk unaided (Verhoef et al. 2006). Although many children with spina bifida go on to lead independent, productive and happy adult lives, they do require ongoing and often intensive medical care. Caregivers need to set up appointments, take the child for care, and maintain vigilance, in addition to helping with toileting, locomotion, and other daily activities.

Caring for children with special health care needs can have both positive and negative consequences for parents (Loebig 1990). Caregivers of children with special health care needs, typically biological mothers, have been reported to be at an increased risk for various health-related problems (Barnett and Boyce 2005; Cameron et al. 2006; Kuster and Merkle 2004; Raina et al. 2005; Stewart et al. 1994; Vermaes et al. 2005). On the other hand, health problems and emotional distress can be offset by psychological well-being associated with successful mastery and social support (Cameron et al. 2006) and overcoming adversity (Joseph and Linley 2006). Although some families have difficulties coping with the demands of caregiving, most adapt successfully and many report increased family cohesion (Taanila et al. 1996).

Primary caregivers typically spend a disproportionate amount of time and energy in caring for their child with special needs (Barnett and Boyce 1995; Crowe and Florez 2006). Greater condition severity is reported to be more commonly associated with negative impacts on family caregivers (Mulvihill et al. 2005). In particular, caregiving strain is associated more with caring for individuals with behavioral or psychiatric conditions than caring for those with physical or cognitive impairments (Busch and Barry 2007; Maes et al. 2003).

The paper has two objectives: to compare time use, health, and indicators of well-being for caregivers of children and adolescents with spina bifida in relation to caregivers of unaffected children and to compare these same measures among caregivers of children with spina bifida relative to lesion location. Our hypotheses are: (1) Compared to unaffected children, the long term care required by children with spina bifida can negatively impact caregiver health and well-being; (2) Higher lesion level is associated with a greater risk for negative effects of caring for a child with spina bifida.

Methods

We used data from a representative sample of families of children and adolescents in Arkansas with spina bifida. Many previous studies of caregiver impacts have been based on samples of families enrolled from specialty centers (Raina et al. 2005) or family support groups (Barnett and Boyce 1995), both of which could contain a disproportionate number of more severely affected children. In this analysis, the families were enrolled from a population-based registry of birth defects, the Arkansas Reproductive Health Monitoring System (ARHMS).

Using AHRMS, we identified 208 families who were caring for a child or adolescent with spina bifida aged 0–17 years born in Arkansas and resided in the state as of 2001–2002. A letter announcing plans for the study was sent to each family, followed by a telephone call asking for permission to interview an adult family member. Of the 208 families, 120 were able to be contacted by telephone. Among the 120 who were contacted by telephone, 98 (82%) agreed to participate, for an overall response rate of 47% among eligible households. A detailed description of the study design and interview response rates can be found elsewhere (Tilford et al. 2005).

All data were obtained by telephone interviews over a 2-year period (2001–2002) with the primary caregiver. Caregivers were asked whether they received the letter announcing the plans for the study and to consent to participate in the study. Informed consent obtained over the phone was documented by the research assistant in the study progress notes. The research assistant asked about the health status of the child as well as the caregiver. The interview took approximately 30 minutes to complete. There was no incentive payment for participation.

In order to obtain comparison data for caregivers of unaffected children**,** interviewers asked respondents to provide the names of up to three families with children that they knew. Forty-one (42%) respondents provided names and addresses for a total of 78 families, and letters describing the study were sent to the 78 nominated families. Contact was made with 57 families, of whom 53 (91%) agreed to participate, for a response rate of 68%. Four families in which a child had a severe disability (Down syndrome, cerebral palsy, muscular dystrophy, and blindness) were excluded, and the remaining 49 families formed the comparison group. The same procedures were employed in obtaining information on controls as with cases. A letter was sent to the family informing them of the study. They were then contacted by telephone to consent to participate in the interview. Finally, the interview was conducted via telephone.

Because the comparison group was not a representative population sample, we also matched caregivers with a representative sample of households with either a married woman or female head with at least one child present under the age of 18 years selected from the Arkansas portion of the March supplement to the Current Population Survey (CPS) during the period 2001–2002. This strategy identified 416 comparison caregivers. However, the only outcome variable that was available from the CPS sample was divorce.

The survey included questions used for the Quality of Well-Being (QWB) scale, which is a preference-weighted health-related quality of life measure that has been found to be particularly sensitive in capturing mental health outcomes (Kaplan et al. 1998; Pyne et al. 2003) and is widely used (e.g., Groessl et al. 2007; Pyne et al. 2008). Respondents were asked to report on their own health state across four subscales: acute and chronic symptoms/problems, mobility, physical activity, and social and self-care activity. Each of the subscales have associated preference weights (scores) derived from a representative community sample. The algorithm for preference-weighting health states uses a categorical rating scale method and a multi-attribute utility model. The preference-weighted subscale scores are subtracted from 1.0 (perfect health) to determine the total QWB score. The higher the subscale score, the greater the impairment associated with that subscale. Analyses presented below used total and subscale scores based on subject responses averaged across the most recent 6-day period.

An additional six questions regarding the self-reported physical and mental health status of the primary caregiver: general health, how often the caregiver is nervous or calm (two questions), how often the caregiver reports being happy, and two questions about feeling depressed (feeling "blue" or "down in the dumps") were adapted from the well-known 36-Item Short-Form Health Survey (SF-36) (McHorney et al. 1993). Survey questions also addressed the amount of time that caregivers reported having been engaged in working for pay (weeks last year and hours per week), sleeping (usual hours per night), visiting with friends at home or in friend's home (days in last 30 days), and participating in leisure activities (days in last 30 days).

We performed Pearson's Chi square test for categorical variables (one or no leisure days in previous months, no visits made to friends in previous month, no friends hosted in previous month, happy some of the time or never, feeling blue more than a little of the time, fair or poor health) and *t* test for continuous variables (mean hours of sleep, mean QWB score for caregiver) between families not affected by spina bifida and families affected by different lesion level of spina bifida. We repeated the analysis stratified by age group in order to examine the interaction between child age and spina bifida lesion. We also examined linear regression analysis on the association of spina bifida with hours of sleep and QWB scores and logistic regression on the association of spina bifida with lack of leisure, fair or poor self-reported mental, emotional, and overall health controlling for sociodemographic variables, including the age, race, education level, marital status of the caregiver and age and sex of the child. All analyses were performed using Stata 8.

Results

Descriptive information about the characteristics of caregivers and their children is provided in Table 1. The respondents in the first group were 98 caregivers of children with spina bifida, comprised of 94 mothers, 1 father, and 3 grandmothers who ranged in age from 24 to 70. The 49 comparison caregivers were comprised of 48 mothers and 1 father and ranged in age from 25 to 60. Caregivers and children in spina bifida-affected families tended to be older than those in comparison families. Comparison caregivers were more likely to have graduated from college (39% vs. 17%; $p < 0.01$) and to be currently married (92% vs. 78%; $p < 0.05$). The distribution of children with spina bifida by lesion level was 41% sacral, 33% lower lumbar, and 24% upper lumbar/thoracic. There were no significant differences of caregiver characteristics among different lesion level of spina bifida except whether the caregiver had a college degree.

Table 1 Comparison of sociodemographic characteristics of caregivers and their children

Characteristic	Affected children	Affected children, by lesion level			Comparison
	Total[a]	Sacral[b]	Lower lumbar[c]	Higher lumbar[d]	Total[e]
Caregivers' mean age (SD)	37.7 (8.9)	38.5(8.5)	38.2(8.5)	35.6(10.2)	34.2 (6.4)**
Child's mean age (SD)	9.3 (4.6)	9.4(4.6)	9.4(4.6)	9.0(4.8)	7.1 (4.0)**
Child's sex					
Female (%)	61.2	61.0	61.0	62.5	55.1
Caregiver's race					
Black (%)	6.1	12.2	0.0	4.2	4.1
White (%)	90.8	80.5	100	95.8	93.9
Caregiver's education level					
<High school grad. (%)	11.2	9.8	15.2	8.3	2.0
High school grad. (%)	41.8	48.8	30.3	45.8	36.7
Some college or trade school (%)	29.6	29.3	27.3	33.3	22.5
College grad. (%)	17.4	12.2	27.3	12.5	38.8**
Caregiver's marital status					
Divorced (%)	13.3	7.3	15.3	20.8	4.1
Married (%)	77.6	82.9	75.6	70.8	91.8*

[a] $n = 98$, [b] $n = 41$, [c] $n = 33$, [d] $n = 24$, [e] $n = 49$

* $p < .05$, ** $p < .01$, two-tailed tests

We hypothesized that time use, health, and other indicators of well-being for caregivers of children with spina bifida differ from those of caregivers of unaffected children and that among caregivers of children with spina bifida these measures would decrease as lesion location increased. Our findings are summarized below according to the measure employed.

Caregivers' Use of Time

As shown in Table 2, there was a significant differential in sleep time between comparison caregivers and spina bifida caregivers (7.0 vs. 6.5, $p < 0.01$) and a significant differential between higher lumbar and sacral lesion groups (6.1 vs. 6.8, $p < 0.05$). Significant differences also were observed in reported days of leisure. About 28% of the caregivers of children with spina bifida reported having 1 or no days of leisure in the previous month, compared to fewer than 5% of comparison caregivers ($p < 0.01$). This varied significantly with the level of child's lesion: 15% among those in the sacral level group, 30% among those in the lower lumbar group, and 46% among those in the upper lumbar/thoracic group ($p < 0.01$). The regression results were similar, indicating that the bivariate differences were not affected by differences in the distributions of observed covariates (Table 3). In bivariate analyses stratified by child age, the differences between sacral and higher lumbar lesion in hours of sleep and lack of leisure days were substantially greater in magnitude and significant only for caregivers of younger children, 0–6 years of age (Table 2). Finally, although a step function (dose-response) pattern was observed in the percentage of caregivers who reported not visiting a single friend in the previous month and in the percentage who had not hosted a friend in their own home in the previous month, the differences were not statistically significant.

Table 2 Average daily hours of sleep, lack of leisure and social activities, fair or poor self-reported mental, emotional, and overall health percentages and mean QWB scores among caregivers, by child's spinal bifida status

Characteristic	Affected children, total, 0–6, 7–17	Affected children, by lesion level			Comparison
		Sacral	Lower lumbar	Higher lumbar	
Mean hours of sleep (SD)	$6.5(1.3)^{a}$	$6.8(1.4)^{b}$	$6.5(1.2)^{c}$	$6.1(1.4)^{d\wedge}$	$7.0(1.1)^{e}$**
Ages 0–6	$6.3(1.4)^{f}$	$6.7(1.2)^{g}$	$6.4(1.4)^{h}$	$5.6(1.7)^{i\wedge}$	$7.0(1.1)^{j}$*
Ages 7–17	$6.6(1.5)^{k}$	$6.8(1.5)^{l}$	$6.5(1.2)^{m}$	$6.4(1.1)^{n}$	$7.1(1.1)^{o}$*
One or no leisure days in previous month (%)	27.6	14.6	30.3	$45.8^{\wedge\wedge}$	4.1**
Ages 0–6	38.2	21.4	27.3	$77.8^{\wedge\wedge}$	4.0**
Ages 7–17	21.9	11.1	31.8	26.7	4.2*
No visits made to friends in previous month (%)	21.4	14.6	24.2	29.2	10.4
Ages 0–6	20.6	7.1	27.3	33.3	12
Ages 7–17	21.9	18.5	22.7	26.7	8.7
No friends hosted in previous month (%)	21.7	10.0	27.3	$33.3^{\wedge}$	24.5
Ages 0–6	20.6	14.3	18.2	33.3	20
Ages 7–17	22.2	7.7	31.8	$33.3^{\wedge}$	29.2
Happy some of the time or never (%)	20.4	12.2	21.2	$33.3^{\wedge}$	6.1*
Ages 0–6	20.6	14.3	9.1	44.4	8.0
Ages 7–17	20.3	11.1	27.3	26.7	4.2**
Feeling blue more than a little of the time (%)	32.7	31.7	27.3	41.7	12.2**
Ages 0–6	52.9	50.0	54.6	55.6	12.0**
Ages 7–17	21.9	22.0	13.6	33.0	12.5
Fair or poor health (%)	14.3	14.6	9.1	20.8	4.1
Ages 0–6	17.7	21.4	18.2	11.1	0.0*
Ages 7–17	12.5	11.1	4.6	26.7	8.3
Mean QWB score for caregiver (SD)	0.76(0.1)	0.77(0.1)	0.77(0.1)	$0.72(0.1)^{\wedge}$	0.8(0.1)*
Ages 0–6	0.74(0.1)	0.74(0.1)	0.75(0.1)	0.74(0.1)	0.79(0.1)
Ages 7–17	0.77(0.1)	0.79(0.1)	0.78(0.1)	$0.71(0.11)^{\wedge\wedge}$	0.81(0.1)

^{a} $n = 98$, ^{b} $n = 41$, ^{c} $n = 33$, ^{d} $n = 24$, ^{e} $n = 49$, ^{f} $n = 34$, ^{g} $n = 14$, ^{h} $n = 11$, ^{i} $n = 9$, ^{j} $n = 25$, ^{k} $n = 64$, ^{l} $n = 27$, ^{m} $n = 22$, ^{n} $n = 15$, ^{o} $n = 24$. * $p < .05$, ** $p < .01$, two-tailed tests of difference between case and comparison groups. ^ $p < .05$. ^^ $p < .01$, two-tailed tests of difference between higher lumbar and sacral level case groups

Table 3 Relationship between caregiver sleep, leisure, mental and general health and different levels of spina bifida, relative to no spina bifida

	Sacral Adjusted odds ratios[a] (95% confidence intervals)	Lower lumbar	Higher lumbar
Mean hours of sleep	−0.23(−.78,.31)	−.50(−1.1,.07)	−.96(−1.6, − .31)**
QWB score for caregiver	−.02(−.06,.03)	−.01(−.06,.03)	−.07(−.12, − .01)*
More than one leisure day in previous month	.25(.04,1.6)	.08(.01,.42)*	.04(.007,.26)**
Whether feeling happy more than a little of the time	.63(.11,3.4)	.2(.04,.97)*	.2(.04,1.1)
Feeling blue more than a little of the time	4.2(1.3,13.7)*	3.0(.87,10.1)	5.8(1.6,21.2)**
Whether in good or better health	.37(.06,2.3)	.70(.09,5.3)	.21(.03,1.4)

[a] Controlling for caregiver age, race, and education, family structure, and child age and sex

* $p < .05$, ** $p < .01$, two-tailed tests

Caregivers' Physical and Mental Health

Of the six questions adapted from the SF-36, significant bivariate differences were observed on three items (Table 2). No significant differences were observed for the items about how often the caregiver reported being nervous, calm, or "down in the dumps". The percentage of caregivers in the sacral lesion group who reported that they were not happy much or all of the time was lower than in either the lower lumbar group (21%) or the upper lumbar/thoracic group (33%) ($p < 0.05$). The percentage in the comparison group (6%) was significantly less than spina bifida group ($p < 0.05$). The percentage that reported feeling blue more than a little of the time was 32% among caregivers of children with spina bifida, compared with 12% in the comparison group ($p < 0.01$), with a similar pattern in the multiple regression results (Table 3). This percentage did not vary significantly by the level of their child's lesion, although it was highest (42%) was among caregivers of children with the highest lesion levels (Table 2). Caregivers of young children with spina bifida were most likely to feel blue, whereas there was no variation by child age among comparison caregivers (Table 2). Finally, differences in the prevalence of self-reported fair or poor physical health were statistically significant only for the caregivers of young children.

We found a modest association between caregivers' health and child's spina bifida status. Specifically, mean caregiver QWB scores were 0.77 for the sacral and lower lumbar groups and 0.72 for the thoracic/higher lumbar group (Tilford et al. 2005). The average QWB score for the thoracic/higher lumbar group was significantly lower relative to the lower lesion groups (0.72 vs. 0.77, $p < 0.05$) and the QWB score for the comparison group was significantly higher than for the spina bifida caregiver group (0.80 vs. 0.76, $p < 0.05$) (Table 2). Regression results were almost identical (Table 3). Unlike hours of sleep, a significant difference in caregiver QWB scores was observed only for the caregivers of older children or adolescents (Table 2).

Divorce

The percentage of caregivers who were divorced varied by lesion level (Fig. 1). We observed a step pattern in the frequency of divorce by lesion level: 7% in the sacral level group, 15% in the lower lumbar level group, and 21% in the thoracic/upper lumbar level group, although the differences were not statistically significant. The probability of caregivers being divorced was associated with mobility limitations: 4 (8%) of 49 caregivers of children aged 5 or older who had either no or mild limitations in mobility had been divorced, compared with 8 (26%) of 31 who reported that their children either had no use of their legs or required someone to lift them.

The percentage currently married was significantly lower among caregivers of children with spina bifida relative to the study comparison group (92% vs. 78%, $p < 0.05$) (Table 1), but not relative to the CPS comparison group. The percentage divorced was 10% in the CPS comparison group compared with 4.1% in the study comparison group.

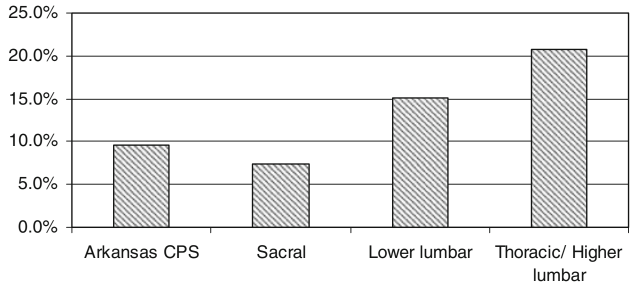

Fig. 1 Percentage of caregivers of children with spina bifida who are divorced, stratified by their child's spina bifida status and level of lesion, relative to matched observations from Arkansas sample, Current Population Survey, 2001

Discussion

In this study, we have found that primary caregivers of children and adolescents with spina bifida on average reported less sleep and engaged in leisure and social activities less frequently than comparison caregivers. These findings are consistent with previous findings (Joosten 1979). However, the way that comparison caregivers were recruited weakens the ability to draw any inferences from these comparisons. More importantly, similar differences were observed within the sample of caregivers of children with spina bifida classified by the child's level of lesion. In particular, for several outcome measures, caregivers of children with the lowest or sacral lesions had self-reported outcomes similar to the comparison caregivers. For those measures, it makes little difference if one restricts the analysis to the sample of caregivers of children with spina bifida and interprets the results classified by lesion level in terms of the impacts of spina bifida on caregivers.

Lack of sleep and reduced time for leisure and social activities, compounded by the stress of taking care of a child who may be in pain or discomfort, can take a toll on the well-being of caregivers. One of the most salient findings in this study was the loss of sleep time by primary caregivers among caregivers of young children with upper lumbar/thoracic lesions relative to those with sacral level lesions. Lack of sleep has been shown to negatively affect people's emotional and physical health (Meltzer and Mindell 2006). Caregiver self-reported quality of life was found to be negatively associated with perceptions of greater pain, sensory impairments, and emotional problems but was not related to ambulation or need for assistance. In other words, caregiving per se does not appear to have negative associations with caregiver health.

Our finding that primary caregivers of children with spina bifida were about twice as likely as other caregivers to report feeling "blue" more than a little of the time is consistent with the findings of one previous study (Carr et al. 1983). However, a significant difference was not found within the spina bifida group classified by lesion level. Also, no significant difference was observed on how often caregivers reported being "down in the dumps.". Although perceptions of support from others in providing childcare has been shown to mediate the likelihood that the mother of a child with a disability will feel depressed (Herman and Marcenko 1997), social isolation experienced by caregivers could negatively affect their perceptions of such support.

The findings of this study address the important question of whether the severity of a child's disability influences caregiver well-being. This is important because, as the result of improvements in medical technology, many children with severe disabilities survive infancy and live well into adulthood (Vermaes et al. 2005). These children are almost all cared for in the home, usually by a parent, and the intensive level of care needed to provide for them has been shown to affect the physical and emotional well-being of the caregiver (Kuster and Merkle 2004). We found that the level of children's spina bifida lesion, which is highly predictive of the severity of disability, is significantly associated with caregiver's sleep time and lack of leisure time among caregivers of children less than 7 years of age, with QWB scores for caregivers of children 7–17 years of age, and with rarely feeling happy overall. Lesion level did not vary significantly with the frequency of self-reported depressive symptoms or overall self-reported health. Previous studies did not find the severity of a child's condition to be significantly associated with maternal depressive symptoms (Manuel et al. 2003) or parental stress (Kronenberger and Thompson 1992; Macias et al. 2003). There is a need for further studies of the relationship between the severity of a child's illness and the health and well-being of the child's caregiver.

Among caregivers of children with higher lumbar/thoracic lesions, 33% reported feeling "not happy most of the time," and 42% reported "feeling blue more than a little of the time." The percentage of respondents who reported being in "fair or poor health" was also highest among caregivers of children with upper lumbar/thoracic lesions. These children often require more intensive care and attention than children with lower level lesions, and the stress associated with providing long-term care for them has been associated with a decline in the caregiver's own health (Kuster and Merkle 2004). Special attention needs to be paid to caregivers of medically fragile children to ensure that their physical, mental, and emotional health needs are being met and that they receive adequate support.

We found a slightly higher percentage of divorce among caregivers of children with spina bifida than among comparison caregivers. A few previous studies which involved small numbers of families also reported a higher frequency of divorce among parents of children with spina bifida (Kolin et al. 1971; Martin 1975; Tew et al. 1977). The frequency of divorce was three times higher among caregivers of children with the highest lesion levels than among those with the lowest level lesions and three times higher among those whose children could not walk as among those whose children had no major mobility limitations, but we cannot exclude the probability that these associations might be due to chance. Research is needed to understand the impact of a child's disability and health problems on marital satisfaction and family functioning. A recent study reported that the frequency of divorce is lower among parents of children with Down syndrome than in the general population (Urbano and Hodapp 2007).

The emotional and mental health problems experienced by caregivers may also affect their physical health. Caregiving mothers of children with chronic conditions have reported lacking time to meet their own needs, feeling fatigued, needing personal time and rest, engaging in limited outside activities, and feeling that their relationship with their partner was affected by the demands of caregiving (Stewart et al. 1994). It does not appear to be the caregiver role per se that causes strain but the extent to which the role impedes the ability of caregivers to fulfill their own needs and function in other roles. Social support, including emotional support and assistance from spouses and informational support from health care professionals, has been shown to help caregivers cope with the daily stresses of caregiving (Hughes and Caliandro 1996; Kuster and Merkle 2004; Stewart et al. 1994). Such support for single mothers, in particular, might be particularly critical.

Limitations of this analysis include a reliance on cross-sectional parental reports. Longitudinal data would be needed to address questions such as the impact of a caregiver's mental health or well-being on her child's health and vice versa. Because of budget and time constraints, the survey questionnaire did not measure such things as stress experienced by caregivers, family functioning, or the effects of spina bifida on siblings of the affected child. Because the comparison group was not a representative population sample, the comparisons are subject to bias, even after adjusting for measured covariates. For this reason, we place greater emphasis on results of the relation between outcome variables and the level of lesion within the spina bifida sample. The inclusion of internal controls in terms of children with relatively mild disorders because of a low lesion level is a unique strength of this study. Another limitation is that we were unable to assess the extent to which the sample of families that responded to the survey differed from those families that were unable to be contacted or did not respond. Finally, the data all came from one state, and it is uncertain to what extent the findings are generalizable to other populations.

The main implication of this study for clinicians and policy makers is that they need to understand how caring for a child with a disability affects the well-being of parental caregivers. Policies and services should be designed and put in place to support parental caregivers of children with special needs. However, we should not assume that such caregivers experience serious difficulties. Among the caregivers of children in this study with the most severe spina bifida lesions, approximately 80% had *not* been divorced, approximately 80% reported having good-to-excellent health, and approximately 70% reported having exchanged social visits with friends in the previous month. Although we did find elevated rates of problems among caregivers of children and adolescents with spina bifida, most caregivers have adapted successfully to the strain and challenges they face in caring for their children.

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