

Cross-informant agreement between adolescents with myelomeningocele and their parents

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The development of self-management skills by adolescents with myelomeningocele is an ongoing process. Previous studies lack consensus about what data can be accurately obtained from adolescents. This cross-sectional study using a convenience sample of 66 adolescent-parent dyads evaluated whether adolescents with myelomeningocele and their parents are interchangeable reporters of data. Adolescents' ages ranged from 12 to 21 years with a mean of 16 years 2 months (SD 2y 8mo); 38 were female, 28 were male; 30% had thoracic lesions, 32% had lumbar lesions, 15% had lumbosacral lesions, 23% had sacral lesions, and 85% had ventriculoperitoneal shunts. In this analysis, participants reported activities (decision-making, household responsibility, and friendship activities) and select outcomes (functional status, self-management, and social competence) similarly. However, differences emerged in reports of beliefs (adolescent future expectations, family variables) and select developmental competencies (school, job, athletic, behavioral, attractiveness, and romantic appeal). Analysis using *t*-test and interclass correlations supported a pattern of adolescent-parent agreement in areas of observable behavior and differences in more subjective domains such as perception of developmental competencies.

Advances in healthcare and technology have dramatically increased the lifespan of children with chronic health disorders (Meleski 2002). More individuals are surviving past adolescence and into adulthood, thus changing the focus of healthcare during adolescence. Healthcare providers working with these adolescents need simultaneously to be sensitive to the adolescent perspective, help adolescents develop autonomy, and understand the perspective of the family. One challenge that providers encounter in this transition process is determining what data can be obtained from either the adolescent or parent interchangeably and which perceptions are unique and need to be collected from both perspectives.

While the use of multiple informants offers a more holistic understanding of adolescent health and ultimately fosters independence in these adolescents (Huberty et al. 2000), using multiple informants may, at times, be impractical. Collecting data from adolescents in a private clinical visit is ideal (Shenkman et al. 2003). Knowing which data are interchangeable between parent and adolescent reporter can assist the healthcare provider in structuring the most useful clinical encounter. The minimal literature available regarding adolescents versus adults as informants frequently indicates differing perceptions when reporting information.

One population facing these new challenges for self-management is adolescents born with myelomeningocele (Blum et al. 1991). Myelomeningocele, which can involve both physical disability and mental retardation*, is the second most common physical disability (after cerebral palsy) of youth today. Adolescents need to learn to manage this complex chronic condition that typically involves urological, orthopedic, neurological, gastrointestinal, integumentary, and psychosocial challenges.

However, if myelomeningocele is well managed most adolescents with this chronic condition can anticipate life expectancy similar to their peers without chronic health conditions, with recent data suggesting at least 75% of children born with myelomeningocele can be expected to survive into adulthood (Bowman et al. 2001). Consequently, healthcare providers working with these adolescents need to emphasize adolescent autonomy and understand their perspective as well as those of their families. Little data exist to guide the clinician in their choice of informant for health information.

STUDIES ADDRESSING CROSS-INFORMANT AGREEMENT

Studies that address cross-informant, adolescent-parent agreement generally fall into three categories reflecting distinct adolescent populations: adolescents without chronic conditions; adolescents with behavioral and/or emotional conditions; and adolescents with chronic physical health conditions.

No studies were found exploring cross-informant differences in adolescents with learning difficulties. Studies evaluating perceived competence in cross-informant and intra-individual data in adolescents without chronic conditions found no or small differences in cognitive or social competence between the reports of adolescents and their parents and reports of mothers and teachers (Steele et al. 1996). In contrast, Stanton et al. (2000) found parents' reports of risk behavior were significantly different and lower than those reported by the adolescents themselves.

See end of paper for list of abbreviations.

*UK usage: learning disability.

The majority of studies evaluating cross-informant agreement in behavioral and/or emotional health used either the Child Behavior Checklist (CBCL) or a structured questionnaire and evaluated adolescent–parent agreement. The highest agreement was reported for symptoms that were concrete, severe, and unambiguous (Herjanic and Reich 1982). The studies found small (Rapee et al. 1994), no (Lee et al. 1994), or similar (Stanger et al. 1996) correlations between children’s self-ratings and ratings by parents, teachers, and healthcare professionals. In general, agreement among adult raters was greater than that between youth and adults (Huberty et al. 2000).

Finally, the cross-informant studies of adolescents with chronic physical health conditions addressing adjustment or quality of life in children and adolescents with cancer or epilepsy found small to moderate relationships between the parent and the child or adolescent, with physical functioning and disease treatment-related symptoms having the largest correlation and social and cognitive functioning the smallest (Varni et al. 1995, 1998). Two studies of functional status (Sawin and Marshall 1992, Young et al. 1995) found high correlations, lending support to adolescents as reliable reporters of functional status.

In summary, we found conflicting data on the cross-informant differences between adolescents and the adults in their lives on a wide variety of variables. The mixed findings highlight the need for further study of cross-informant data, especially as it pertains to adolescent versus parent reports. In addition, no data are available specific to the population of adolescents with myelomeningocele and their parents. Given the subtle psychosocial and cognitive issues many adolescents with myelomeningocele face, understanding their level of agreement with their parents on these variables can be very useful to healthcare providers.

This study aimed to fill these gaps by evaluating whether there are differences in reports between adolescents with myelomeningocele and their parents in the domains of adolescent activities, beliefs, and outcome competencies.

Method

DESIGN

This report is a portion of a larger descriptive correlational study that evaluated adaptation in adolescents with myelomeningocele (Sawin et al. 2003b, Buran et al. 2004). The larger study was reviewed and approved by the institutional review board of Indiana University. This analysis addressed the cross-informant differences on study measures.

The research question was: are there differences between adolescents with myelomeningocele and their parents on measures of adolescent activities (adolescent decision-making participation, chores/household responsibility, and friendship activities), beliefs (future expectations, family cohesion, adaptability, satisfaction, and activities), and outcome competencies (functional status, self-management/independence, and developmental competencies)?

SAMPLE

We recruited a convenience sample of 66 adolescents with myelomeningocele and their primary caregiving parent/legal guardian seen in a specialty clinic at Riley Hospital for Children, Indianapolis, Indiana. We contacted eligible adolescents and their parents by letter of invitation and by personal invitation

during a clinic visit. Adolescent inclusion criteria included: (1) age of 12 to 21 years; (2) no major medical condition (i.e. life-threatening, progressive, or incapacitating disability) other than myelomeningocele; and (3) functioning within 2 years of grade level in school.

The adolescent may have been in a resource program but not in a moderately mentally retarded or severely mentally retarded class. The sample was limited by excluding adolescents who were not functioning at grade level, as many of the measures are not valid in those with delayed cognitive functioning. All participants and their parents signed informed consent or assent forms before participation in the study.

INSTRUMENTS

Table I outlines the instruments used in this analysis and their reliabilities in this study. Readers may refer to Sawin et al. (2003b) and Buran et al. (2004) for additional description of these variables.

The structured interview was conducted by trained health professionals. Each family was either interviewed in the home/community setting (32%) or via telephone (68%). Selected questionnaires were completed by mail.

ADOLESCENT ACTIVITIES

Decision-making participation, chores and/or household responsibilities, and activities with friends were measured by the Adolescent Activities Inventory (AAI; Sawin and Marshall 1992). Previous factor analysis has supported the reliability and existence of a one-dimensional scale for chores, but two subscales for the Peer Activities Scale and three subscales for the Decision-making Scale. Because the third Decision-making Scale had low reliability it was not used in this analysis.

BELIEFS

Future expectations

The 14-item Future Expectation Scale measures adolescents’ confidence that they could achieve future expectations in relationships, school, jobs, and accomplishments. Participants respond to this 14-item, Likert-type scale using a 5-point response pattern.

Family variables

The concepts of family cohesion, family adaptability, family satisfaction, and family activities were measured by three scales. First, the Family Adaptation and Cohesion Evaluation Scale (FACES II), a 20-item scale with 10 items for each concept, measured cohesion, and adaptability.

Second, we measured satisfaction by using the 5-item Family Apgar and a revised version of the same scale for children (Smilkstein et al. 1982, Austin and Huberty 1989). Both have substantial reliability and validity reports. Finally, the family activities scale is a parallel scale to the scale for peer activities described above in the AAI. Participants report how often the adolescent takes part in activities with family members.

OUTCOME COMPETENCIES

Functional status

The Functional Independence Measure for Children (WeeFim[®]; Ottenbacher et al. 1996), an 18-item scored structured interview that measures performance in essential daily functional skills across the domains of self-care, mobility, and

cognition, was created to use with children and adolescents who exhibit functional or developmental delay. Data support the WeeFim® when administered by a trained professional conducting in-person or telephone interviews. This instrument has been used with parents or providers as data sources. No study to date has determined if adolescents themselves are reliable informants for the WeeFim®.

Self-management and independence

We developed the Adolescent Self-management and Independence Scale (AMIS) to measure competencies related to managing conditions that are necessary for the transition from adolescence to adulthood. The structured interview has 10 items addressing issues such as independence in knowing about and taking medicine appropriately, ordering medication and/or supplies, demonstrating advocacy skills, obtaining transportation, managing money, and demonstrating household skills. Preliminary construct validity and reliability has been established. The factor analysis yielded two congruent concepts – self-management and independence.

Developmental competencies

Scales from the Self-perception Profile for Adolescents (SPPA) measured developmental competencies (Harter 1988). The 45-item instrument generates independent measurement of both the adolescent's overall perception or global judgments of self-worth or self-esteem and eight domain-specific competency scales (physical, athletic, job, scholastic, romantic appeal, close friendships, behavioral conduct, and social acceptance). Internal reliabilities vary by scale, but multiple studies report 0.77 to 0.94 for all scales.

The parent version of the SPPA, a parallel 16-item index that uses the same format described above, measures only the eight domain-specific competencies with two items each. Harter maintained that this 16-item scale is appropriate for comparing parents' reports and adolescents' reports on the eight domain-specific competencies. Further, self-esteem is not measured on the parent version as the creator of the profile proposed that a person's overall global judgment of self-worth or self-esteem cannot be determined by others (Harter 1988).

Analysis

Data were analyzed using SPSS (version 11.0). Frequencies were computed for the descriptive data and the scale scores. Percentages are reported for characteristics of the sample and means with standard deviations are reported for scale scores. Internal consistency reliability for each scale and subscale was calculated using Cronbach alpha: those values are reported in Table II. Scale/subscale reliabilities in this study were generally acceptable. Two subscales (adaptability and romantic appeal) were below the $\alpha=0.70$ standard and need to be interpreted with caution. Paired *t*-tests were used to assess differences between individual adolescent-parent pairs, and interclass correlations (ICC) were used to examine the level of agreement between raters while correcting for chance agreement. No separate analysis was carried out by sex due to the small sample size.

Results

Adolescents' ages ranged from 12 to 21 years with a mean of 16 years 2 months (SD 2y 8mo). Ninety percent of the study sample was white, which reflects the geographic area of the clinical program where data were collected. Of the adolescents studied,

Table I: Measures used in this study

<i>Variable</i>	<i>Instrument</i>	<i>Number of items</i>	<i>Scores range</i>	<i>Reliability^a</i>
Adolescent activities				
Decision-making participation	Adolescent Activities Inventory (AAI) Decision-Making Scale	20	1–5	0.87
Household responsibility	Chores Scale	14	1–3	0.79
Peer activities	Peer Activities Scale	13	1–5	0.72
Beliefs				
Future expectation	Future Expectation Scale	16	1–6	0.83
Family variables				
Cohesion	Family Adaptation and Cohesion Evaluation Scale (FACES II)	10	1–5	0.84
Adaptability	FACES II	10	1–5	0.63
Satisfaction	Family Apgar	5	1–4	0.75
Activities	Family Activities Scale (AAI)	13	1–5	0.79
Outcome competencies				
Functional status	Functional Independence Measure for Children (WeeFIM®)	18	1–7	0.91
Self-management	Adolescent Self-Management and Independence Scale	10	1–7	0.87
Developmental competencies				
	Self-Perception Profile for Adolescents			
	Scholastic competence	5	1–4	0.80
	Job competence	5	1–4	0.74
	Athletic competence	5	1–4	0.83
	Behavioral conduct	5	1–4	0.74
	Close friendship	5	1–4	0.84
	Physical appearance	5	1–4	0.86
	Romantic appeal	5	1–4	0.56
	Social acceptance	5	1–4	0.80

^aReliabilities reported for adolescent sample.

58% were female, 42% were male. Furthermore, 69% lived in two-parent families, 19% lived in single-parent households with the mother as the head of the household, and 9% lived in single-parent families with the father as the head of the household. The adolescents' families were fairly well-educated, and the majority of both of the parents were employed. The average length of education for fathers was 12 years 4 months and for mothers was 13 years. Although this was a convenience sample, the sample was similar to the clinic population in sex (58% female in study, 53% clinic) and years of age (study mean 16y 2mo, clinic mean 15y 8mo; study median 15y 8mo, clinic median 15y 1mo).

The level of spinal cord lesion for the adolescents with myelomeningocele was distributed as follows: 30% (19) had thoracic lesions, 32% (20) had lumbar lesions, 15% (9) had lumbosacral lesions, and 23% (14) had sacral lesions and 0.6% (4) had other lesions. Most of the adolescents (85%) had ventriculoperitoneal shunts.

Table II summarizes the frequencies and *t*-tests between cross-informants. Table III summarizes the Pearson's correla-

tions and ICC. The decision-making, chores, and friendship scores were fairly low in this sample, with adolescents and parents reporting that the adolescent participated in decision-making a moderate amount, never, or occasionally did chores, and rarely or sometimes participated in activities with peers. However, the adolescents felt that they could accomplish future tasks, while the parents were less sure. Both adolescents and parents described the family climate as sometimes to frequently cohesive and frequently organized. Also, both reported satisfaction with their family. In addition, both groups reported that the adolescent was independent in areas of self-care and mobility with the use of assistive devices, but needed moderate assistance with self-management.

In contrast to similar ratings across the adolescent-parent pair on concrete, observable adolescent activities and competencies such as decision-making, household responsibility, friendship activities, functional status, self-management, and social competence, differences across the pairs emerged in beliefs and developmental competencies. Specifically, we observed significant differences between raters in future

Table II: Frequencies, paired *t*-test, and mean difference between adolescent and parent values

Measure	Parent mean (SD)	Adolescent mean (SD)	Paired <i>t</i> -test	Paired <i>t</i> -test significance	Mean difference (SD)	95% CI of difference
Adolescent activities						
Decision-making						
Participation						
Family decision-making	2.6 (0.81)	2.9 (0.90)	-1.90	0.06	-0.22 (0.84)	-0.44 to 0.01
Activities decision-making	2.7 (0.65)	2.8 (1.0)	-1.20	0.25	-0.11 (0.69)	-0.28 to 0.07
Total	2.7 (0.65)	2.8 (0.72)	-1.50	0.11	-0.12 (0.58)	-0.02 to 0.27
Chores	1.7 (3.8)	1.6 (3.0)	1.70	0.10	0.06 (0.26)	-0.01 to 0.13
Friendship activity 1	2.9 (0.92)	2.8 (0.84)	0.65	0.52	0.06 (0.75)	-0.13 to 0.26
Friendship activity 2	3.5 (1.0)	3.5 (1.1)	0.23	0.82	0.03 (0.99)	-0.23 to 0.29
Beliefs						
Future expectations	4.3 (0.63)	4.5 (0.60)	-2.20	0.03	-0.19 (0.66)	-0.37 to 0.02
Family variables						
Cohesion	3.7 (0.64)	3.5 (0.80)	1.90	0.07	0.22 (0.88)	-0.01 to 0.44
Adaptability	2.3 (0.63)	2.5 (0.62)	-0.28	0.77	-0.03 (0.69)	-0.21 to 0.16
Satisfaction	3.7 (0.80)	3.8 (0.73)	0.86	0.39	0.12 (1.0)	-0.15 to 0.38
Family activities	3.2 (0.68)	3.0 (0.69)	3.40	0.00	0.30 (0.67)	0.12 to 0.48
Outcome competencies						
Functional status						
Self-care	45.0 (11.2)	45.8 (10.0)	-0.88	-0.38	-0.75 (0.85)	-2.4 to 0.95
Mobility	26.5 (8.7)	26.9 (9.1)	-0.81	0.42	-0.33 (3.1)	-1.1 to 0.48
Cognitive	32.3 (3.2)	32.5 (3.6)	-0.46	0.65	-0.17 (2.8)	-0.93 to 0.58
Total	105.3 (19.5)	102.9 (22.7)	1.1	0.25	2.4 (15.9)	1.7 to 6.5
AMIS						
Self-management	3.8 (1.5)	3.7 (1.6)	0.14	0.89	0.02 (0.80)	-0.25 to 0.22
Independence	4.3 (1.4)	4.3 (1.3)	0.15	0.88	0.02 (1.0)	-0.28 to 0.33
Total	3.7 (1.1)	3.7 (1.2)	0.22	0.83	0.02 (0.63)	-0.16 to 0.20
Developmental competence						
Scholastic competence	3.0 (0.80)	2.5 (0.78)	5.8	0.00	0.53 (0.72)	0.34 to 0.71
Job competence	3.3 (0.86)	2.9 (0.83)	1.9	0.06	.32 (1.1)	0.02 to 0.66
Athletic competence	1.7 (0.91)	2.0 (0.86)	-2.5	0.01	-0.35 (1.1)	-0.63 to 0.07
Behavioral conduct	3.6 (0.70)	3.2 (0.77)	3.8	0.00	0.42 (0.86)	0.20 to 0.65
Close friendship	3.0 (1.1)	3.3 (0.88)	-1.5	0.13	-0.23 (1.2)	-0.53 to 0.07
Physical appearance	3.7 (0.50)	2.6 (0.96)	8.9	0.00	1.1 (0.94)	0.84 to 1.3
Romantic appeal	2.2 (1.0)	2.6 (0.78)	-2.4	0.02	-0.34 (0.97)	-0.62 to 0.06
Social acceptance	2.9 (1.0)	2.9 (0.84)	0.36	0.72	0.05 (1.1)	-0.23 to 0.34

AMIS, Adolescent Self-management and Independence Scale; CI, confidence interval.

expectations and five of the eight Harter scales. Whereas parents' mean scores were significantly higher than adolescents' ratings in the areas of perception of scholastic achievement, physical attractiveness, and behavior, adolescents' mean scores in perception of athletic ability and involvement in romantic relationships were significantly higher than parents' ratings.

Although adolescents' mean scores in the areas of perception of peer relationships and close friendships were higher than parents' and parents scored higher in the opinion of employment performance, none of the difference was at a significant level.

Of interest, when examining the data from the adolescent and parent groups as a whole, we found strong ICC (0.60–0.85) for adolescent activities, while only weak to moderate relationships emerged in the analysis of family data with the lowest ICC found in the family satisfaction. Finally, while a low agreement was observed for job competency ratings, moderate agreement emerged across the other developmental competencies.

Discussion

The most striking finding of our research was the lack of difference in reports for many measures, a significant contrast

to the majority of previous studies that found differences across a range of domains of functioning. While differences between adolescents and their parents in subjective beliefs are relatively established in the literature, less clear is when these family members report consistent data, especially in clinical encounters.

We have the most confidence that the adolescents' and parents' reports were clinically interchangeable in this sample in areas where there was no difference using *t*-test scores and strong ICC ($r=0.70$ or higher).

This study provides evidence that for this sample, adolescents and their parents are interchangeable reporters of adolescent decision-making, responsibility, friendship activities, functional status, self-management, and social competence. The clinical relevance of these findings is that healthcare professionals may justifiably use one informant to obtain information in such areas of agreement. However, we found that the interchangeability of reporters across future expectations, family variables, and developmental competence domains other than social could not be supported.

Interestingly, the strong adolescent–parent agreement may be unique to the myelomeningocele population. For example, other families of adolescents with chronic conditions have

Table III: Pearson and interclass correlations (ICC) between parent and adolescent report

<i>Variables</i>	<i>Pearson's correlation (significance)</i>	<i>Interclass correlation (significance)</i>	<i>95% confidence interval of ICC</i>
Adolescent activities			
Decision-making total	0.65 (0.00)	0.78 (0.00)	0.63 to 0.87
Family decision-making	0.53 (0.00)	0.70 (0.00)	0.47 to 0.82
Activities decision-making	0.75 (0.00)	0.85 (0.00)	0.75 to 0.91
Chores/Household responsibilities	0.73 (0.00)	0.83 (0.00)	0.71 to 0.90
Friendship activity 1	0.64 (0.00)	0.78 (0.00)	0.61 to 0.86
Friendship activity 2	0.58 (0.00)	0.72 (0.00)	0.54 to 0.83
Beliefs			
Future expectations	0.43 (0.00)	0.60 (0.00)	0.31 to 0.76
Family variables			
Cohesion	0.27 (0.04)	0.41 (0.02)	0.01 to 0.65
Adaptability	0.32 (0.02)	0.48 (0.01)	0.01 to 0.69
Satisfaction	0.10 (0.45)	0.18 (0.22)	−0.37 to 0.51
Family activities	0.51 (0.00)	0.68 (0.00)	0.46 to 0.81
Outcome competencies			
Functional status			
Self-care	0.82 (0.00)	0.90 (0.00)	0.83 to 0.94
Mobility	0.94 (0.00)	0.97 (0.00)	0.95 to 0.98
Cognitive	0.65 (0.00)	0.78 (0.00)	0.63 to 0.87
Total functional status	0.81 (0.00)	0.90 (0.00)	0.82 to 0.95
AMIS			
Self-management	0.87 (0.00)	0.93 (0.00)	0.87 to 0.96
Independence	0.72 (0.00)	0.83 (0.00)	0.70 to 0.91
Total	0.81 (0.00)	0.90 (0.00)	0.82 to 0.95
Developmental competencies			
Scholastic competence	0.58 (0.00)	0.46 (0.01)	0.09 to 0.68
Job competence	0.11 (0.48)	0.19 (0.23)	−0.46 to 0.55
Athletic competence	0.28 (0.03)	0.44 (0.00)	0.05 to 0.67
Behavioral conduct	0.32 (0.01)	0.48 (0.01)	0.13 to 0.69
Close friendship	0.30 (0.02)	0.45 (0.01)	0.09 to 0.68
Physical appearance	0.31 (0.01)	0.40 (0.00)	−0.01 to 0.64
Romantic appeal	0.44 (0.00)	0.59 (0.00)	0.27 to 0.77
Social acceptance	0.29 (0.03)	0.45 (0.00)	0.06 to 0.67

AMIS, Adolescent Self-management and Independence Scale.

been characterized as having high conflict or disagreement (Anderson et al. 1999, Cuneo and Schiaffino 2002). While adolescents did report some conflict over independence, neither the parents' nor the adolescents' qualitative data reflected high conflict between parents and adolescents in these families (Sawin et al. 2003a). This population has been found to be more passive, perhaps less rebellious, and have fewer peers than other teenagers do (Holmbeck et al. 2002). In addition, adolescents with myelomeningocele spent more time on activities with their families than with their peers without chronic conditions or peers with other chronic conditions, an unusual finding for adolescents (Buran et al. 2004). Finally, it is unclear what role, if any, learning difficulties have on adolescent insight and self-reporting. Clearly, the findings of this study may not be clinically applicable for those with other chronic conditions.

The differences in adolescents' and parents' reports in the domain of developmental competencies are important for healthcare providers to understand. We noted the largest difference in the area of physical attractiveness, in which parents viewed their adolescents as much more attractive than the adolescents did. In fact, a large majority of the parents reported the optimal score of 4 in this area, a clear discrepancy from their adolescents' mean score of 2.6. Parents in this study had similar patterns of 'disagreement' on developmental competence as parents of adolescents without myelomeningocele reported in the literature. Unclear and important for future study is whether any other variable, such as depression, accounts for lack of agreement in adolescent-parent dyads with myelomeningocele (Youngstrom et al. 2000).

A pattern of adolescent-parent agreement in areas of overt, observable behaviors and differences in more subjective, less concrete domains, such as perception of developmental competencies, is consistent with previous studies that investigated cross-informant agreement (Varni et al. 1998, Huberty et al. 2000).

It is important to note, however, that unlike the other measures administered to participants in our study, the eight Harter subscales used to measure adolescent and parent perceptions of the adolescent's developmental competencies had scales of differing lengths, a five-item adolescent scale, and a two-item parent scale. While the use of non-identical measures must be considered when examining data from the developmental competencies, support for the observed difference across raters in the more subjective, intrinsic dimensions of adolescent behavior comes from prior research that similarly found differences in adolescents' and parents' reports in these areas (Herjanic and Reich 1982, Steele et al. 1996). Moreover, adolescents and parents in our study reported significantly different perceptions of future expectations, despite the use of identical measures.

Transition planning, including the transfer of responsibility for healthcare decisions from the parent to the adolescent with myelomeningocele, ought to unfold in a stepwise fashion throughout adolescence (Blum et al. 1991). Importantly, data from studies of other chronic conditions indicate optimal health outcomes when parents turn over the responsibility for the care of a condition to their adolescent gradually and in a supported environment. One area to foster independence in adolescents with myelomeningocele is to heighten their participation in providing data in interactions with healthcare

providers. To facilitate adolescent empowerment, the structure of clinic visits may need to be altered with a general identification of concerns obtained from parent and adolescent jointly and then the history and examination conducted in private. The family could be reunited for a summary session at the end of the visit. Encouraging adolescents to participate more actively and independently in their health decisions via direct communication with the health professional may ultimately enhance long-range independence for the transitioning adolescent.

Importantly, not all data from our study suggest that adolescents with myelomeningocele and their parents may serve as interchangeable reporters. To ensure that a comprehensive understanding of the adolescent's overall well-being is established by health professionals serving this population, obtaining information from both reporters in areas where obvious differences or mixed results emerged (e.g., developmental competencies) is clearly desirable.

In summary, adolescents and their parents gave similar reports of many of the more concrete observable activities (decision-making, household responsibility, and friendship activities) and outcome competencies (functional status, self-management, and social competence) evaluated in this study. We found differences in future expectations, family variables, and five developmental competencies. The characteristics of the sample limit the ability to generalize these findings to others with myelomeningocele or other chronic conditions, especially if samples differ from this one in race, family structure, socioeconomic status, and chronic conditions. In addition, the study was limited by the inability to include IQ level in the analysis of the data. Further study is warranted to determine if similar findings exist within other populations and to explore factors associated with cross-informant differences.

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List of abbreviations

AAI	Adolescent Activities Inventory
AMIS	Adolescent Self-management and Independence Scale
CBCL	Child Behavior Checklist
FACES II	Family Adaptation and Cohesion Evaluation Scale
SPPA	Self-perception Profile for Adolescents
WeeFIM®	Functional Independence Measure for Children

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Notification and Call for Papers

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