

Myelomeningocele, Temperament Patterns, and Parental Perceptions

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ABSTRACT. *Objective.* Description of temperament profiles of children has largely been reported in typically developing populations. Children undergo individualized assessments of achievement (developmental/academic) and receive individualized interventions. In contrast, their individual behavioral styles are not evaluated as completely, if at all. For children with developmental disabilities, description of temperament characteristics can provide better understanding of the already complex child. This study describes temperament characteristics in a group of children with myelomeningocele and shunted hydrocephalus (MM/SH).

Methods. A consecutive cohort study with historical control group measuring temperament characteristics was conducted at a tertiary-level, university affiliated, interdisciplinary spina bifida program. Analysis includes group comparisons. Primary caregivers of 46 children (age range: 5–12 years) with MM/SH completed age-appropriate Carey Temperament Scales questionnaires as a component of a larger developmental study. The Carey Temperament Scales comprise a series of behavioral rating instruments that assess 9 temperament characteristics: activity, adaptability, approach-withdrawal, mood, intensity, attention/persistence, distractibility, sensory threshold, and rhythmicity/predictability. The Carey questionnaires used in this study were (1) the Behavioral Style Questionnaire for children aged 5 to 7 years and (2) the Middle Childhood Temperament Questionnaire for those aged 8 to 12 years. Both questionnaires assess the same temperament characteristics; the contexts within which items were rated were designed to better reflect developmental levels. Children were excluded when there were comorbid diagnoses of attention-deficit/hyperactivity disorder or mental retardation.

Results. One-sample normal tests (Bonferroni corrected) revealed that children within the MM/SH group differed significantly from the standardized population in 5 dimensions: (1) adaptability (less adaptable), (2) approach/withdrawal (poor first approach/greater withdrawal), (3) distractibility (more distractible), (4) attention/persistence (less attentive/persistent), and (5) predictability/rhythm (less predictable). Caregiver perceptions of having a difficult-to-manage child were significantly correlated with negative mood, more intensity of response, and less adaptability.

Conclusions. Temperament profiles previously described in typically developing populations (eg, “easy”

or “difficult child”) were not prominent profiles in this group of children with MM/SH. A constellation of temperament characteristics not commonly recognized may place these children at risk for being contributors to and recipients of misunderstandings of social cues and have implications for successful learning within academic, home/community, and medical settings. *Pediatrics* 2005; 115:e58–e63. URL: www.pediatrics.org/cgi/doi/10.1542/peds.2004-0797; *hydrocephalus, myelomeningocele, temperament, parental perceptions, early intervention.*

ABBREVIATIONS. MM, myelomeningocele; SH, shunted hydrocephalus; CTS, Carey Temperament Scales; BSQ, Behavioral Style Questionnaire; MTQ, Middle Childhood Temperament Questionnaire.

Spina bifida is the leading cause of infantile paralysis in the world today, with the incidence rates varying at ~1 per 1000 live births.¹ Myelomeningocele (MM), a more severe form of spina bifida, is identified when there is a bony defect in the spine, protrusion of the neural tissue from the spinal cord, and a lack of skin covering the defect.² This complex condition, resulting from a neurodevelopmental disruption early in gestation, affects not just the spine but also the central nervous system as a result of the ventriculomegaly and Chiari malformation commonly present.

Children with MM have benefited from advanced surgical interventions and interdisciplinary medical specialty care with resulting improvement in morbidity and mortality.³ Consequently, the anticipatory interventions of pediatricians have expanded beyond management of life-threatening neonatal complications. Increasingly, the dimensions of quality-of-life issues, prevention of secondary disabilities, and participation in broader community activities have taken their rightful place among the various priorities.

Growing interest has also focused on the psychosocial, medical, and cognitive characteristics within this population and their combined impact on learning and community participation.^{4–19} The ultimate goal of related research is the establishment of appropriate interventions and support systems, applied in early childhood, that will presumably have positive influence in the transition to adolescence and adulthood. One central component in this process of intervention involves acknowledgment of the infant/child's temperament characteristics and the parent's ability to read and respond accordingly.

Temperament has been described in typically developing populations as the “how” of behavior—

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distinct from ability (“what” of behaving) and motivation (“why” of behavior).^{20–22} Dimensions of temperament used in developmental pediatrics include those described by Chess and Thomas.²¹ These dimensions are defined in Table 1. Implicit within the conceptualization of temperament is the notion of multiple behaviors along a continuum, which combine to interact either favorably or unfavorably with the surrounding environment. These constellations of behaviors do not reflect pathologic characteristics or define environments that are excessively stressful. Rather, the potential for pathologic development lies within the process of the interaction—the “goodness of fit”—between the child and the caregiver’s behavioral responses. Consonance between the child and his or her environment potentiates optimal development and supportable teachable moments. Conversely, dissonance has the potential to reinforce patterns of maladaptive functioning.^{21,22}

In typically developing children, temperament characteristics have proved to be predictors of later academic achievement, quality of mother–child and teacher–child interactions, specific problem behaviors, and general health of the child.^{22–28} Among children with developmental disabilities, variations in temperament characteristics may create challenges to the pediatrician and may cause confusion to parents as they try to interpret behaviors in their “at risk” child. The neurodevelopmental variations in MM, associated with ventricular, cortical, and limbic differences in anatomy and function, support the idea of potential important differences in the arena of temperament.^{12,29} Unique temperament styles should be considered in this population and could provide better understanding of individual differences among children with MM/shunted hydrocephalus (SH).

TABLE 1. Definitions of Temperament Dimensions

Dimension	Definition
Activity	Motor component in a child’s functioning and diurnal proportion of active and inactive periods
Rhythmicity/predictability	Regularity of biologic functions (eg, feeding, sleeping, elimination)
First reaction (approach-withdrawal)	Nature of the initial response to a new stimulus (new food, toy, person) whether approach/withdrawal
Adaptability	Responses to a new or altered situation
Intensity of reaction	Energy level of a response
Mood	Amount of pleasant, joyful, friendly behavior versus unpleasant, crying, or unfriendly behavior
Distractibility	Effect of extraneous stimuli in interfering with ongoing behavior
Persistence	Continuation of an activity in the face of obstacles
Threshold of responsiveness	The intensity level of stimulation necessary to evoke a discernible response

Furthermore, it is known that a caregiver’s perceptions of the child affects that dyad’s quality of interaction^{20,22,30,31} and is a likely contributor to the “goodness of fit” between parent and child. For parents of children with MM with widely varying neurodevelopmental differences, the ability to separate temperament styles from other physiologic or pathologic causes of “difficult” or challenging behavior can be a deterrent to optimal dyad interaction. Determining which temperament characteristics parents deem most difficult to manage therefore is necessary when counseling parents on how to create supporting environments for their child with MM.

To date, the only report of temperament as a contributor to overall adjustment among children with MM suggests that “the difficult” child profile correlated with poor psychological adjustment.³² What remains to be described is whether general patterns of temperament styles exist to guide practitioners’ approach to this population.

To address these issues, this study investigated 9 dimensions of temperament in a group of children with MM/SH in comparison with that of nondisabled, age-matched population norms. We also investigated whether caregivers’ overall perceptions of their child’s temperament matched their actual item ratings of the child’s temperament within each of the 9 dimensions. Finally, to describe parental perceptions of “difficult behavior,” we investigated the cluster of temperament characteristics deemed by parents to be most challenging.

METHODS

Participants

Primary caregivers of 46 children with MM/SH (32 girls aged 5–12 years; mean age: 9.1; median: 8.5) were asked to complete temperament questionnaires as part of a larger developmental study. Children who lived throughout the state of Texas were recruited from the Spina Bifida Program at Texas Scottish Rite Hospital for Children (Dallas, TX), where they receive ongoing subspecialty care.

The majority of children ($n = 34$) lived with both biological parents (in all of these cases, the mother filled out the questionnaire), 2 had grandfathers listed as primary caregivers, 8 lived with a single parent (mother in 7 cases, father in 1 case), and 2 children were legally adopted (in this case, the adoptive mothers filled out the questionnaire). The range of occupations of the caregivers based on the Hollingshead Four Factor Index³³ ranged from professional to unskilled, representative of both high- and low-income backgrounds, but the majority were in the middle-income group. Education backgrounds ranged from completion of high school to graduate level professional training, with the majority of caregivers having at least 2 years of baccalaureate training.

A white-American background was claimed by 69.6% ($n = 32$) of the total sample, 15.2% ($n = 7$) reported a Latin-American or Hispanic background, 10.8% ($n = 5$) reported an African-American background, and 4.3% ($n = 2$) reported an Asian-American background. A majority had functional lesions classified at the lumbar level (76.1%), 5 had sacral level lesions, and 6 had thoracic lesions.

Inclusion criteria used were (1) diagnosis of MM and Arnold Chiari II; (2) a ventriculoperitoneal shunt placed before 12 months of age; (3) monolingual (English) background; (4) average intelligence; (5) if a history of seizures, neither seizures nor changes in anticonvulsant medications for 3 months before the study. Exclusionary criteria were (1) any previous shunt infection, (2) shunt revision/malfunction within the previous 3 months, (3) uncorrected auditory or visual acuity deficits, (4) previous diagnosis of

attention-deficit/hyperactivity disorder or mental retardation, and (5) previous diagnosis of clinical depression.

Measures

The Carey Temperament Scales (CTS) comprise a series of age-adjusted scales that assess 9 categories of temperament characteristics on the basis of earlier work by Thomas and Chess²¹ (Table 1). Scales used were the Behavioral Style Questionnaire (BSQ) for children aged 5 to 7 years and the Middle Childhood Temperament Questionnaire (MTQ) for those aged 8 to 12 years.^{34,35} Identical temperament characteristics were evaluated; changes in question construct were designed and validated to better reflect developmental levels. Approximately 30 minutes was required for completion of the questionnaire. Specific items on the BSQ and MTQ provide ratings on a 6-point scale of behavior styles demonstrated by the child. On the basis of these item ratings, category-rated scores for each of the 9 temperament domains described in Table 1 are generated.

In addition to the temperament scaled items, the questionnaires elicit caregivers' general perceptions of how "manageable" their child is compared with other children or siblings of the same age. In contrast to the items, which asked for a rating of the frequency of specific behaviors, these questions require the rater to compare the child with other children the same age as their child. These general impressions elicit a final global perception of the child's temperament scored using a 6-point scale (1 = very easy, 6 = very difficult).

Data analysis

For comparison of children with MM/SH with their age-matched population norms, scores for each temperament category were converted to z scores (using published norms for each age group) and analyzed using a 1-sample normal test (Bonferroni corrected to account for multiple comparisons). This was done to determine whether the mean of the MM/SH group was significantly different from 0 at a Bonferroni-adjusted *P* value of .005. Test normative data were derived from typically developing children, predominantly white-American and of middle socioeconomic status living in the eastern United States.³⁶ No information was provided regarding family characteristics (single vs 2-parent home) or educational background of the caregiver.

The temperament category-rated scores were compared with 2 measures of caregiver perceptions of the child's temperament: general perceptions of each temperament category and an overall rating of the child's degree of difficulty. Spearman correlations were computed between responses on the caregivers' general estimates of their children in the 9 temperament categories and their respective category-rated scores. Correlations between overall caregiver perceptions of the degree of difficulty and the category-rated scores were also computed. Effects of gender, age, and lesion level on temperament category scores were investigated using Spearman correlations.

RESULTS

Temperament clusters of "easy," "difficult," and "slow to warm" described by Chess and Thomas²¹ were not noted among this cohort of children with MM/SH. On average, all scores fell within the average range (between ± 1 SD), but differences from the typically developing population of children were clearly found.

In addition to low activity, children in the MM/SH group differed significantly from their age-matched population norms in 5 additional temperament domains: (1) adaptability (less adaptable; *P* < .001), (2) approach/withdrawal (poor first approach/greater withdrawal to a new stimulus; *P* = .001), (3) distractibility (more distractible; *P* = .004), (4) attention/persistence (less attentive/persistent to a task; *P* < .001), and (5) rhythmicity/predictability (less predictable in terms of biological functions; *P* < .001). Descriptive statistics for the 9 temperament domains

for the children with MM are depicted in Table 2 and illustrated in Fig 1.

Positive correlations were noted between parental ratings and perceptions for 6 of the 9 temperament dimensions (Table 3). When considering the distribution of the caregivers' general impressions of degree of temperamental difficulty, 17.39% rated their child as being difficult compared with other children of the same age. Caregivers' perceptions of having a "difficult-to-manage child" were significantly correlated with negative mood (*r* = .45, *P* = .0015), stronger intensity of response (*r* = .39, *P* = .006), and less adaptability (*r* = .47, *P* = .001). No significant differences were detected regarding gender, age, or lesion levels (*P* > .05).

DISCUSSION

No single modal profile of temperament for children with MM/SH was identified in this study, but the clusters found did not follow the profiles described by Chess and Thomas in an otherwise typically developing sample. Specifically, children with MM/SH were rated by their caregivers as being more negative in their first response to new stimuli, being less adaptable, less persistent when completing a task, more distractible, and less predictable in biological function in comparison with their age-matched, nondisabled peers.

These temperament characteristics in each child, subsequently moderated or enhanced through life experiences and shaped from the responses of surrounding individuals, are important features when family members, educators, and health care professionals interact with youths with MM/SH in the various environments encountered. The "goodness of fit" underlying successful interactions—such as supportive, teachable moments—may, in part, require the recognition of these temperament characteristics.

Brazelton³⁷ has encouraged pediatricians to counsel young parents of typically developing children regarding behavioral characteristics as part of anticipatory guidance. Carey^{20,38} expanded on the importance of pediatricians' understanding of clusters of temperament styles and their impact on social and school performance. Perhaps the most notable description of clusters of temperament styles remains that of Chess and Thomas.²¹ They identified 3 recur-

TABLE 2. Descriptive Statistics for Temperament Variables (*N* = 46)

Temperament Domain	Mean (SD)	95% Confidence Interval
Activity*	-0.71 (0.86)	(-0.97, -0.46)
Rhythmicity/predictability*	0.83 (0.83)	(0.58 to 1.07)
First reaction (approach-withdrawal)*	0.54 (1.0)	(0.23 to 0.84)
Adaptability*	0.64 (0.83)	(0.39 to 0.89)
Intensity of reaction	-0.25 (0.91)	(-0.52 to 0.02)
Mood	0.46 (1.2)	(0.11 to 0.81)
Distractibility*	0.37 (0.83)	(0.12 to 0.61)
Persistence*	0.91 (0.79)	(0.67 to 1.1)
Threshold of responsiveness	0.13 (0.87)	(-0.13 to 0.39)

* *P* < .005.

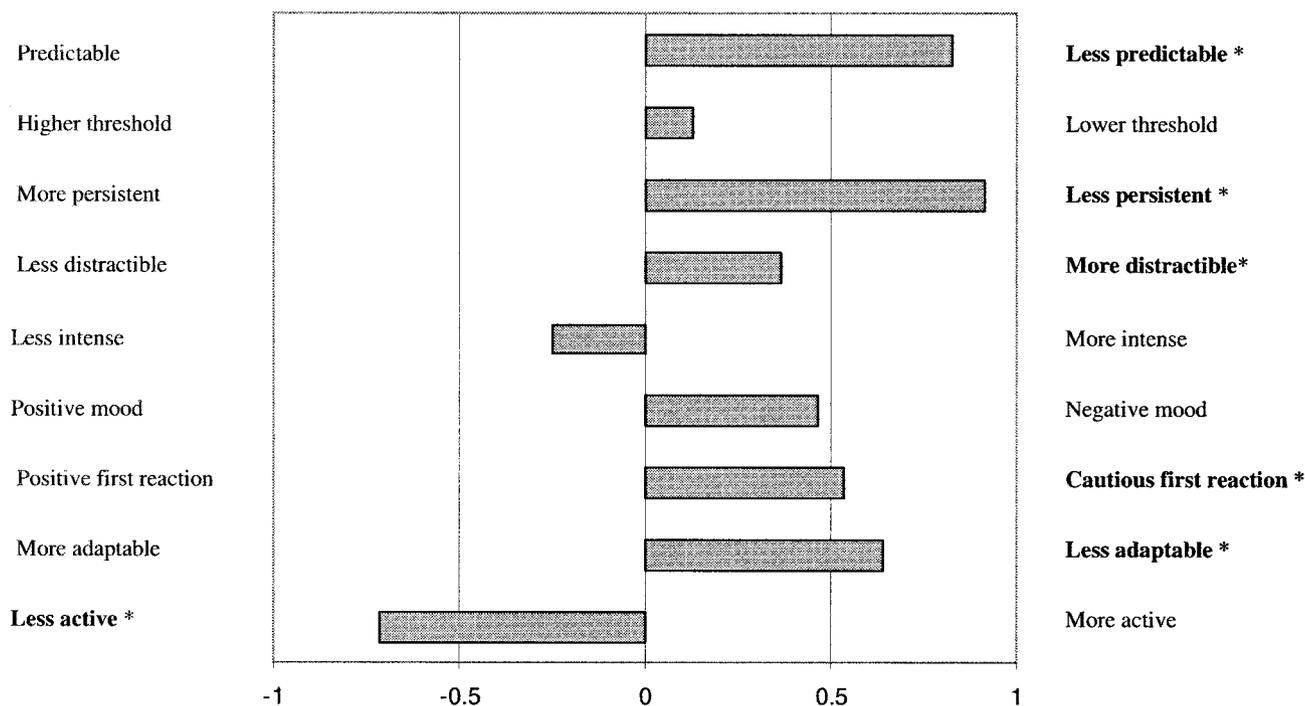


Fig 1. Domains of temperament: children with MM/SH compared with nonaffected test norms using z scores (mean = 0). * $P < .005$.

TABLE 3. Correlations Between Caregiver Actual Ratings and Perceptions on Each Temperament Dimension

Temperament Dimension	Rating Versus Perceptions (<i>r</i>)
Activity	.19
Rhythmicity/predictability	.14
First reaction	.63*
Adaptability	.19
Intensity	.53*
Mood	.49*
Distractibility	.54*
Persistence	.52*
Threshold	.40*

* $P < 0.01$.

ring groups in their studies: the “easy” child, the “slow-to-warm” child, and the “difficult” child. These 3 clusters described in the developmental-behavioral pediatric literature did not occur prominently within this group of children with MM/SH. Unfortunately, a constellation of temperament characteristics not commonly recognized may place these children at risk for being contributors to and recipients of misunderstandings of social cues.

Over the past decade, increasing interest in and knowledge of family dynamics in relation to children with disabilities has continued to emerge. The percentage of children who were rated as difficult to manage by their caregivers in this sample of children with MM/SH was somewhat higher (17.39%) than that reported for the typically developing population (10%).²⁰ Caregiver perceptions of having a “difficult-to-manage child” were significantly correlated with negative mood, stronger intensity of response, and less adaptability. Studies of adaptation strategies among mothers of children with MM/SH attest to the significant stressors that can come to serve as the

foundation on which these parents are expected to function.^{18,39–41} There is substantial evidence that child temperament influences parenting stress in children with chronic disabilities.⁴² It is hardly unexpected that the feelings and emotional reserve of caregivers would have an impact on the quality of “read and respond” when interacting with the child with MM/SH. A better understanding of the child’s individual temperament profile, within the context of the underlying neurodevelopmental differences, may positively shape the caregiver–child interaction.

Carey^{20,23} described concern in parents and teachers when the child’s temperament is challenging, unintentionally reinforced, and eventually incorporated into the child’s coping strategies. He and others suggested that this pattern ultimately contributes to a “poorness of fit” in both academic and social realms.^{20,23,25,26,31} In our children with MM/SH, a cluster of “at risk” behavioral styles involved negative responses to new stimuli (low approach), to changes in routine (low adaptability), and to extraneous distractions (high distractibility) and the ability to maintain persistent focus (poor persistence). Studies indicate that teachers rated the combination of low persistence, low approach, and low adaptability as difficult to manage in nonaffected children with learning differences.^{25,43,44} Academic/social challenges and barriers are well documented among youths with MM.^{9–11,13–16,45,46} Layers of seemingly separate but simultaneous factors—cognitive, memory, language, temperament, and physical—can elevate even daily and mundane tasks into sources of stress that are not experienced by the typical classmate. The result often manifests as poor output performance.

The differences in temperament profiles among

children with MM in this sample differed from those in other diagnostic cohorts of children with special health care needs.^{42,47-51} Suskauer et al⁵¹ studied the temperament patterns of children with osteogenesis imperfecta and compared them with age-matched norms. This group represents a cohort, like those with MM/SH, who have a congenital condition with chronic manifestations that affect orthopedic issues and motor development. Unlike children with MM/SH, they do not have underlying central nervous system variations related to the brain ventricles, the midbrain, or the hypothalamic axis. As might be expected, there were no statistical differences between the osteogenesis imperfecta cohort of patients and the normative scales for age-matched control subjects except in the activity domain.

The impact of the brain differences among the MM/SH group is critical to the question of temperament patterns among these children.²⁹ For children with MM/SH, there are remarkable variations in brain development prenatally in both cortical and subcortical regions. Additional impact can potentially occur in the postnatal period related to hydrocephalus development, the surgical act of shunt placement, and the robustness of their environmental exposures. In a recent report regarding typically developing children, the relationship of cortisol activation to their reactivity and self-regulation when placed in a stressful environment (kindergarten entry) was described.⁵² Preliminary findings suggested that cortisol response differences were related to their infant and toddler environmental experiences. Given the variations noted above in children with MM/SH, this offers an interesting link to differences in response styles potentially related to temperament.

To allow substantive data collection and to maintain research methods that support the internal validity of this study, we acknowledged and accepted several constraints in design for reasonable completion of project. First, control groups were recognized only in the CTS normative data. Children with MM/SH in this study were compared with the CTS normative data derived from age-matched, typically developing children who shared similar ethnic and socioeconomic backgrounds (predominantly white, middle income). Comparisons with normative data may have masked the role of specific regional differences, family factors (single vs 2-parent home), and educational backgrounds of caregivers. Replication using appropriately matched, typically developing regional control subjects is warranted.

The advantage of using a typically developing group as the comparison group is that typical development is a reference point used by both parents and professionals. However, the unique life experiences of children with chronic medical conditions such as MM/SH must be considered. Comparisons between these children and children with other chronic medical conditions (closely matched for age, gender, ethnicity, family characteristics, educational background, and socioeconomic status) will further help determine whether commonalities in profiles that are experience driven exist (eg, determined by frequent

hospitalizations, stresses of the illness) or unique temperament trends are seen for the different disorders on the basis of neurodevelopmental variations in the MM/SH group.

A second limitation is that this study reports a 1-time examination of temperament in children with MM/SH and as such is a "snapshot in time" of their temperament characteristics; longitudinal studies that track developmental shifts in temperament from infancy to adolescence will be helpful. Finally, although temperament questionnaire responses can raise concerns of methodologic significance in many studies,⁵³ the perception of behaviors by the caregivers in this case is an important finding to the clinician addressing the "goodness of fit" at play. The majority of caregivers in this study rated their children as being easy to manage in comparison with other children of the same age. Positive correlations were noted between caregivers' general perceptions of their child's behavioral styles and their actual ratings for the majority of the temperament domains. The foci of future research then should be to assess how caregiver perceptions and the child's actual behavioral style influence caregiver interactions within different structured and unstructured situations.

CONCLUSION

The pattern of temperament characteristics described among this group is striking in its consistency and statistical findings. As with other profiles that can too easily become stereotypical among children with MM/SH, this information should provide general guidance to the parent or the professional. Individualized assessments as part of full psychoeducational assessments are needed.

For the typically developing family with a new infant, the joy of parenthood is blended with the learning curve of reading the actions and reactions of the child who might be labeled "easy" or "difficult." On the birth of an infant with MM, the parents commonly experience reactions of crisis, confusion, grief, and/or stress—each of which can act as a barrier to successful parent—infant relationships. For pediatricians, the opportunity to describe the emerging temperament styles of the infant with MM is a "natural" task that can assist in the process of defining "typical" characteristics of the child. This early adaptation process and the ability to respond to temperament differences with the best "goodness of fit" have the potential to enhance the lifelong relationship between parents and child.

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