Stress Appraisal and Coping in Siblings of Children with Special Needs

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ISSN 1918-5227
Pages 166-181

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Stress Appraisal and Coping in Siblings of Children with Special Needs

Melanie Orfus and Nina Howe
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Abstract

Self-reports from siblings of children with special needs regarding their appraisal of family stress and coping are important additions to the disability literature. Twelve school-age siblings of children with special needs were interviewed about their daily hassles, uplifts, and coping strategies related to living in a family with a child with a disability. Parents also reported on family coping strategies. Children reported that the most frequent daily hassle was when their sibling with special needs cried, screamed, or yelled when he/she did not want to do something. The most frequent daily uplift was when their sibling gave hugs or kisses. Children reported feeling most stressed when embarrassed by their sibling with special needs in front of friends and happiest when playing with their sibling. Wishful thinking was a common child coping strategy during stressful times. Implications for working with families with special needs are discussed.

Children with disabilities are exceptional in their functioning; therefore, they are likely to affect the psychological status and resources of the family (Bubolz & Whiren, 1984; Frey, Greenberg, & Fewell, 1989). Hornby and Seligman (1991) asserted that several shifts in thinking and behaviour must take place within the family to help them make sense of the disability’s implications. One such implication is the possible effect on the typically-developing child in the family. Because school-age siblings spend more time with each other than their parents (Larson & Richards, 1994), it is clear that this unique sibling bond can have an immense impact on their lives. For example, siblings have been shown to influence one another’s development (Stoneham, Brody, Davis, & Crapps, 1988) and adjustment (Dunn, 2002). In addition, healthy family development depends upon the emotional health of all its members (Walsh, 1982); therefore, the sibling perspective is important to ascertain. However, the perspective of the typically-developing sibling is sometimes overlooked in the literature on families with a child with special needs (Giallo & Gavidia-Payne, 2006). Thus, the purpose of the present study was to investigate the perspective of 12 siblings concerning their appraisal of stress and coping strategies as related
to their sibling with special needs. Parent reports were also sought to compare similarities and differences between sibling and family coping strategies.

Studies on the effects of disability on siblings have expanded our view of these exceptional families (see Damiani, 1999; Moore, Howard, & McLaughlin, 2002, for reviews). It has been reported that siblings of children with disabilities are at risk for deviancy (Trevino, 1979), lower self-concept (Harvey & Greenway, 1984), and behaviour problems (Cuskelly & Gunn, 1993; Dunn, 1992). Typically-developing siblings may also experience additional caregiving responsibilities (Cuskelly & Gunn, 2003; Nixon & Cummings, 1999; Stoneman et al., 1988) as well as parental differential treatment (Pit-Ten Cate & Loots, 2000), which suggests that these children may experience some stress related to family dynamics. The early landmark study by Grossman (1972) reported that 45% of college-aged siblings of children with special needs had negative feelings, such as shame towards their sibling; although it should be noted that the stigma associated with having a child with a disability was likely more prominent at the time the study was conducted. More recently, Pit-Ten Cate and Loots (2000) examined issues related to peers and the external community and concluded that there were no complications in peer relationships associated with having a sibling with a disability; yet, nearly 20% of their sample (10–18 years old) chose not to tell some people about their sibling with disabilities. In addition, Powell and Gallagher (1993) noted that school-age children experienced conflicted feelings of wishing to be accepted by their peers, while at the same time wanting to defend their sibling with a disability.

Some studies showed no significant differences between typically-developing siblings and comparison children in self-concept, social competence, and behaviour adjustment (Dyson, 1999; Ferrari, 1983), while others reported positive effects of having a sibling with special needs (Pit-Ten Cate & Loots, 2000). Grossman (1972) also found that 45% of the siblings believed they had benefited from having a sibling with cognitive disabilities: They reported increased understanding of other people, more tolerance and compassion, and a greater appreciation of their own good health and intelligence. Positive results have been replicated in more recent studies (Pit-Ten Cate & Loots 2000; Stainton & Besser, 1998). Taken together, these studies suggest that having a sibling with a disability may be associated with some positive benefits as well as stress and may require coping strategies for children to adjust to the family dynamics.

It is important to note, however, that in much of the early literature, parents, specifically mothers, assessed their child’s behaviour and adjustment (e.g., Cuskelly & Gunn, 1993). In general, siblings have been overlooked in the literature and need to participate in the dialogue by voicing their perspectives on family and personal stress and living with a child with special needs. More recently, mothers, fathers, and siblings have been included in the discussion of family functioning (Cuskelly & Gunn, 2003; Ross & Cuskelly, 2006), demonstrating a more systemic view of childhood disability, where challenges are viewed as impacting on the whole family (Walsh, 2003). Existing literature on families with a child with special needs demonstrates a discord between parent and sibling assessments of feelings and adjustment (Giallo & Gavidia-Payne, 2006). In one study, mothers rated typically-developing children as perceiving their sibling’s physical disability more negatively than siblings themselves rated it (Taylor, Fuggle, & Charman, 2001).

The present study investigated how the typically-developing sibling appraised stress and coping. Psychological theorists, who apply adult stress appraisal theories to studying children, do so under the assumption that stress is dependent on the individual’s appraisal of the event (Bosser, 1994; Robson, 1999). This approach provides a strong foundation for assessing children’s
appraisal of stress as long as the child’s perception is considered foremost. Appraisal is divided into two domains (Lazarus, 1966): Primary appraisal describes the individual’s assessment of the personal relevance of the event in terms of well-being, whereas secondary appraisal involves the assessment of the resources accessible for coping. Lazarus (1966) asserted that, as with our psychological structures, the ability to appraise stress develops over time. Lazarus and Folkman (1984) also reported that individuals differ in their sensitivity and vulnerability to events. Children’s developmental differences in appraising and coping with stress become relevant to the present study. Vulnerability is described as the adequacy of the individual’s resources. For example, children’s physical, psychological, and social resources are not as developed as are adults’, and as such, their increased vulnerability may transform into increased threat. Therefore, due to emotional and cognitive differences, a child and an adult even from the same family might perceive, react, and cope with stress in very different ways.

Children’s secondary appraisal, an assessment of one’s coping mechanisms, may also differ from adults’ appraisals. While innate coping begins as soon as a child is born, Brenner (1984) asserted that children will inevitably develop some of their coping mechanisms from their parents, peers, teachers, and relatives. This author further argued that coping cannot be classified neatly into an age-stage list, as numerous effective coping strategies have been reported across the lifespan. Children rarely will use only one strategy at a time, and it is possible that children may not even be conscious of their coping patterns. However, distinguishing whether a child is avoiding or facing stress can be useful (Brenner, 1984). Pit-Ten Cate and Loots (2000) found that sisters of children with physical disabilities actively tried to solve their problems, rather than tolerating them. Avoidance can be displayed through denial (acting as though the stress does not exist), regression (acting younger than their age), withdrawal (removing themselves physically or mentally from the situation), or impulsive acting out. In contrast, altruism (forgetting their trouble by helping others), humour (joking about their stress), suppression (setting aside their stress temporarily), anticipation (foreseeing and planning for the next stressful episode) and sublimation (becoming absorbed in activities) are ways children cope while facing the reality of their stress. All these types of coping may have positive and/or negative outcomes on the child, depending on the extremity of their behaviour (Brenner, 1984).

Other authors distinguished coping in children in terms of internalizing or externalizing behaviours (Achenbach & Howell, 1993; Honig, 1986). Children who cope by internalizing are more likely to accept responsibility and feel remorse for their actions, whereas those who externalize tend to attribute control or fate to others. To add to the growing literature that has obtained the sibling perspective, school-age children with a sibling with special needs were interviewed in the present study to reveal their appraisal of stress. The child’s daily hassles, uplifts, and coping strategies, as well as the family’s adaptation and coping style concerning the disability, were investigated. This systemic view (Walsh, 1982) of a family experiencing childhood disability provides insight into how children and their parents perceive and cope with their unique circumstances and can have promising implications for therapeutic intervention.

**Research Questions**

To investigate the issue of how school-age children with a sibling with a disability assess the levels of stress and their coping mechanisms, we interviewed 12 children and their parents. Due to the constraints of a limited sample size, research questions and responses are considered useful as a springboard for further investigation. The following set of questions was investigated:
What daily hassles/uplifts do siblings of children with special needs experience most often and find most stressful/uplifting? The analysis of the frequency of daily hassles may illuminate if there are common problems or stressors experienced by siblings of children with disabilities. It may also shed some light on any common experiences that consistently elicit stress in the siblings. A review of the children’s reports of daily uplifts may also reveal commonalities and positive benefits associated with having a sibling with a disability.

How do siblings of children with special needs cope with their daily upsets? Children may use many coping strategies in response to stress and we investigated the frequency of 15 common coping strategies reported by siblings of children with disabilities.

Are there developmental and gender differences in sibling stress appraisal? The content of endorsed items was investigated to reveal any developmental or gender differences between children’s appraisal of stress.

How does the family cope with their difficulties? The family’s coping paradigm was also investigated to determine which resources parents reported as most useful. Because the systems literature emphasizes the interdependence and shared meanings of the family structure, this question has relevance for both parents and children. When the family’s adaptation paradigm is clear, future investigations may reveal how children are influenced by their family’s adaptation to the disability.

Method

Participants

Families, including a child with special needs and at least one typically-developing sibling, were recruited from a large, urban, bilingual (French/English) area (pop. = 3,000,000). English-speaking participants were recruited through community centres, schools, word-of-mouth, and a sibling support group. Information packages were distributed to parents after a discussion given by the researcher, or by school or centre employees. Recruitment continued for a period of 5 months, after which point it was suspended in order to begin analysis. In the end, 12 families participated in the study.

All families had between two and four children. The closest-in-age sibling to the child with special needs participated as it was anticipated that these two siblings would spend the most time together. Mean age of typically-developing children was 9.5 years (range 8–12 yrs), 7/12 were younger than their brother or sister with special needs, and gender was evenly distributed (6 girls, 6 boys). The typically-developing siblings were divided into two age groups: older (10–12 years) and younger (8–9 years). These ages were chosen based on several factors. First, Costigan, Floyd, Harter, and McClintock (1997) noted that typically-developing siblings of children with mental disabilities, aged 6 to 12 years, demonstrated the most negative effects as compared with older siblings and controls. They also speculated that this period of middle to late childhood is the most difficult time for these siblings, especially if they are chronologically younger than the sibling with the disability. During this period, a younger sibling’s competencies may surpass that of his/her sibling with a disability, requiring adaptation to the new older sibling role. In addition, this age is often characterized by concrete operational thinking, which may make these
children more sensitive to issues about family rules and differential treatment. School-age children are also able to recognize emotions (Carroll & Steward, 1984; Muris, Hoeve, Meesters, & Mayer, 2004), affirming the child’s capability to assess his/her own stress and coping. Finally, based on developmental differences that occur over middle childhood, Sheets, Sandler, and West (1996) distinguished between older (10–12 years) and younger (8–9 years) school-age children in their examination of children’s responses to divorce.

The children with disabilities ranged from 3 to 14 years with a mean age of 10.08 years (3 girls, 9 boys). Disabilities included Autism, Down syndrome, various chromosomal abnormalities, and Cerebral Palsy. Families were considered middle class based on parental job descriptions (e.g., lab technician, photographer) and level of education (56% of parents had attended university). Four participants attended a monthly sibling support group to discuss their experiences of having a sibling with special needs.

Procedure and Measures

Families were studied in the home setting. Parents, usually the mother, completed the instruments while the first author privately interviewed the typically-developing child in a separate room. Prior to beginning each interview, the researcher established rapport to put the child at ease. Child measures were counterbalanced.

Child measures. Child interviews took about 30 minutes to complete. First, a modified version of the Sibling Daily Hassles and Uplifts Scale was administered (Giallo & Gavidia-Payne, 2005, 2006). This 32-item measure assessed the substance and frequency of daily hassles reported by the sibling and included 22 hassles (e.g., “when my brother/sister with a disability messes up my room”) and 10 uplifting factors (e.g., “when my brother/sister with a disability gives me hugs or kisses”) associated with having a sibling with a disability. The child was asked to rate each item along two dimensions: “how often does the problem happen?” and “how stressed out does the problem make you feel?” The first author read the items and children responded by pointing to a 5-point pictorial scale of circles of increasing size that corresponded to how frequently the event occurred (never; sometimes; always) and how stressed/happy they felt in response to the item (not at all; a little; a lot). For both the hassles and uplifting subscales, a total score each for both frequency and intensity can be obtained. High scores on the hassle subscale indicate a high frequency of hassles and high intensity of affect associated with hassles. High scores on the uplifting subscale indicate a high frequency of uplifting factors and high intensity of affect associated with these positive events. High internal consistency was demonstrated with the original Australian sample. Items in the scale also correspond well with the experiences reported in Pit-Ten Cate and Loots’ (2000) study on siblings of children with disabilities, in which they divided sibling concerns into one of three categories: the sibling relationship, relationship with peers and external community, and relationship with parents.

Secondary appraisal was measured by completing the KIDCOPE measure (Spirito, Stark, & Williams, 1988). This instrument asks the child about his/her coping strategies, both in terms of use of a particular strategy and how much the strategy helped. Siblings were asked to consider their coping strategies used during stressful events surrounding their sibling. For each strategy, the child was asked to answer either “yes” or “no” depending on whether he/she used the strategy or not. If he/she chose yes, he/she was asked to indicate how much the strategy helped by choosing one of three possible answers: not at all, a little, or a lot. The version of this
scale designed for younger children (Spirito et al., 1988) is specifically appropriate for children 7-12 years of age and uses 15 items to measure the frequency and effectiveness of behavioural and cognitive coping strategies. Children were asked to consider an upsetting event concerning their sibling with special needs when completing the measure. The brevity of the instrument is developmentally appropriate for the age of participants in the present study and test-retest reliability is described as adequate (Naar-King, Ellis, & Frey, 2004). Spirito et al. (1988) also noted moderate to high correlations of the KIDCOPE with other coping measures.

**Parent measures.** Parents completed the 30-item Family Crisis-Oriented Personal Evaluation Scale (F-COPES) to assess the family’s coping and adaptation paradigm regarding everyday problems (McCubbin, Olson, & Larsen, 1987). Items (e.g., “Sharing our difficulties with relatives”) were rated on a 4-point scale (never; sometimes; often; most of the time). Items are divided into five subscales. Three scales describe the external family coping style, including acquiring social support from relatives, friends, neighbours, and extended family; seeking spiritual support; and mobilizing the family to acquire and accept help from community resources. Two subscales assess how the family handles their problems internally: (a) reframing, which determines the family’s capacity to redefine stressful situations to make them more manageable; and (b) passive appraisal, which measures the inactive or passive behaviours a family might employ. Alpha is reported at .86 overall with subscales ranging from .62 to .84. Test-retest reliability after 4 weeks for the total scale was .81 (Grotevant & Carlson, 1989).

Parents also completed a short demographic questionnaire assessing areas such as family structure and levels of education. Following the initial data collection, a follow-up survey (four questions) was mailed to parents to probe some of the findings in more depth. The four questions asked about the kinds of coping strategies parents used and sibling behaviour parents observed in more detail (e.g., “Please choose a coping strategy and briefly describe a family example of when you used this strategy”). Eight of the 12 (67%) families completed and returned the follow-up survey.

**Results**

Substantial quantitative connections were hindered by a small sample size, as well as the lack of a comparison group; therefore, research questions are discussed descriptively by conducting a content analysis of the most and least frequently endorsed items. Findings are supported and refined in the Discussion section with qualitative data obtained from the follow-up parent questionnaire. Results are considered relevant for exploratory purposes only, as no generalizations can be drawn from the limited sample.

**Parental Rating of Family Coping Strategies**

According to parents, the most frequent family problem-solving attitude and behaviour in response to problems or difficulties was “accepting stressful events as a fact of life.” The second most frequent strategy was “facing the problem head on and trying to get a solution right away,” followed by the strategy of “showing that we are strong.” All families reported using these three strategies to some degree with 8/12 using them “often” or “most of the time.” Other strategies used by all the families to some degree included “knowing we have the power to solve major
problems” and “accepting that difficulties occur unexpectedly.” The least used coping strategies were “seeking advice from a religious leader,” “asking relatives how they feel about problems we face,” and “knowing luck plays a big part in how well we are able to solve family problems.”

**Sibling Daily Events Ratings**

**Hassles.** The *Sibling Daily Hassles and Uplifts Scale* was employed to measure children’s perceptions of daily hassles associated with their sibling with a disability. Disability specific hassles and uplifts were analyzed by frequency and intensity (see Table 1) and suggest that siblings experience stressors associated with their sibling with special needs; however, they reported more frequent and intense positive experiences. Again, the small sample prevents any meaningful conclusions and results are offered to facilitate exploration. The most frequently reported daily hassle was “when my sibling with a disability cries, screams or yells when they don’t want to do something.” The most stressful item based on the intensity rating was reported as “when my brother/sister with a disability embarrasses me when I have friends over.” The content analyses of children’s endorsement of the items revealed that their responses also varied by age and gender.

(a) **Age.** Frequency and intensity ratings for both age groups are reported in Table 1 and appear to be similar to the overall mean. However, the content analysis of the item endorsement suggested some interesting findings. The most frequently reported daily hassles for the younger siblings were (a) “when my brother/sister with a disability cries, screams or yells when he/she doesn’t want to do something,” (b) “when my brother/sister with a disability cries or gets upset,” and (c) “when my brother/sister with a disability hurts, hits, pushes, scratches or kicks me or others.” The most stressful items for this age group were (a) “when my brother/sister with a disability embarrasses me when I have friends over” and (b) “not being able to do what I want because my brother/sister with a disability interrupts me.”

The most frequently reported hassles for the older age group were the same as the first two reported above for the younger age group, followed by “having to give in to my brother/sister with a disability so he/she does not get upset.” Interestingly, older children endorsed different items than younger children that they found most stressful: (a) “when my brother/sister with a disability cries, screams or yells when he/she doesn’t want to do something,” “when my brother/sister with a disability is sick or hurt,” and (c) “when people don’t understand about my brother/sister’s disability.”

(b) **Gender.** Although the mean for frequency of hassles for girls was slightly above the overall and the boys’ mean, mean intensity scores were the same as for boys (see Table 1). The content analysis indicated that the most frequently occurring hassles for both girls and boys were (a) “when my brother/sister with a disability cries or gets upset” and (b) “when my brother/sister with a disability cries, screams or yells when he/she doesn’t want to do something.” The latter item was the most stressful for girls, followed by “when my brother/sister with a disability takes my things without asking.” Boys endorsed the following items as being the most stressful situations: (a) “when my brother/sister embarrasses me when I have friends over” and (b) “when my brother/sister with a disability cries or gets upset.”
Table 1
Overall Mean Scores and Standard Deviations of Daily Events Scale

<table>
<thead>
<tr>
<th>Overall ratings</th>
<th>Total</th>
<th>8-9 years</th>
<th>10-12 years</th>
<th>Boys</th>
<th>Girls</th>
</tr>
</thead>
<tbody>
<tr>
<td>M (SD)</td>
<td>M (SD)</td>
<td>M (SD)</td>
<td>M (SD)</td>
<td>M (SD)</td>
<td>M (SD)</td>
</tr>
<tr>
<td>Daily Hassles</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>How often does the problem happen?</td>
<td>1.69 (0.63)</td>
<td>1.76 (0.73)</td>
<td>1.59 (0.74)</td>
<td>1.34 (0.66)</td>
<td>2.03 (0.81)</td>
</tr>
<tr>
<td>How stressed out does the problem make you feel?</td>
<td>2.05 (0.64)</td>
<td>2.13 (0.73)</td>
<td>1.79 (1.01)</td>
<td>1.98 (0.77)</td>
<td>1.95 (1.04)</td>
</tr>
<tr>
<td>Daily Uplifts</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>How often does the good thing happen?</td>
<td>2.13 (0.50)</td>
<td>2.03 (0.58)</td>
<td>2.28 (0.56)</td>
<td>2.12 (0.54)</td>
<td>2.15 (0.69)</td>
</tr>
<tr>
<td>How happy does the good thing make you feel?</td>
<td>3.38 (0.19)</td>
<td>3.10 (0.46)</td>
<td>3.59 (0.15)</td>
<td>3.27 (0.27)</td>
<td>3.62 (0.34)</td>
</tr>
</tbody>
</table>

**Uplifts.** According to child reports, the overall mean frequency and intensity of daily uplifts was somewhat higher than for hassles (see Table 1). The content analysis indicated that the most frequently occurring uplifting behaviour was “when my brother/sister with a disability gives me hugs or kisses.” The two behaviours that elicited the most happiness from siblings were (a) “playing together with my brother/sister with a disability” and (b) “spending time with my brother/sister with a disability.” A content analysis of uplifts by age and gender was also conducted for exploratory purposes.

(a) **Age.** The content analysis indicated that younger children reported that the most frequent daily uplifts were (a) “playing together with my brother/sister with a disability” and (b) “spending time with my brother/sister with a disability.” Happiest items for this age were (a) “spending time with my brother/sister with a disability” and (b) “when my brother/sister with a disability tries hard at something.” Older children (aged 10–12 yrs) endorsed the following items as their most frequently occurring uplifts: (a) “when my brother/sister with a disability gives me hugs or kisses” and (b) “when my brother/sister with a disability learns something new.” The items eliciting the most happiness for this age group were (a) “helping my brother/sister with a disability to learn something new,” (b) “playing together with my brother/sister with a disability,” and (c) “when my brother/sister with a disability shares something with me.”

(b) **Gender.** Most frequently occurring uplifts endorsed by girls were (a) “when my brother/sister with a disability gives me hugs or kisses” and (b) “when my brother/sister with a disability does funny things.” Girls reported the following items as eliciting the most happiness: (a) “when my day runs smoothly without interruptions from my brother/sister with a disability,” and (b) “when my brother/sister with a disability shares something with me.” In contrast, boys endorsed these uplifts most frequently: (a) “spending time with my brother/sister with a disabil-
ity,” (b) “playing together with my brother/sister with a disability,” and (c) “when my brother/sister with a disability tries hard at something.” Boys reported that the following items elicited the most happiness: (a) “playing together with my brother/sister with a disability,” (b) “when my brother/sister with a disability shares something with me,” (c) “spending time with my brother/sister with a disability,” and (d) “hearing good news about my brother/sister with a disability.”

**Sibling KIDCOPE Ratings**

The *KIDCOPE* measure assessed children’s secondary appraisal of stress. Children’s coping strategies and descriptive statistics are reported in Table 2. Overall, the ratings indicated that all siblings used emotion-focused coping strategies, specifically wishful thinking and problem-solving strategies. The content analysis of item endorsement indicated that the most commonly used coping item reported by all the children was “I wish the problem had never happened.” Eleven of 12 children used this strategy with 6/11 reporting that it helped “a little” or “a lot.” Other commonly reported strategies (11/12 children) were (a) “I wish I could make things different,” (b) “I try to fix the problem by thinking of answers,” and (c) “I try to fix the problem by doing something or talking to someone.” The two least commonly used items were “I just try to forget it” and “I do something like watch TV or play a game to forget it.” Two coping items were reported as helping the most: “I try to feel better by spending time with others, like family, grownups or friends” and “I try to fix the problem by doing something or talking to someone.” A content analysis of coping according to age and gender was conducted.

(a) Age. The coping items endorsed the most frequently by younger children were (a) “I wish the problem had never happened” and (b) “I try to fix the problem by doing something or talking to someone.” The strategy used the least frequently by this age group was “I keep quiet about the problem.” The coping item reported as helping the most was “I do something like watch TV or play a game to forget it.” The item reported as helping the least was “I don’t do anything because the problem can’t be fixed.” In contrast, older children reported using the strategy “I keep quiet about the problem” most often. Used least often were (a) “I just try to forget it,” (b) “I do something like watch TV or play a game to forget it,” (c) “I blame myself for causing the problem,” and (d) “I try to calm myself down.” The items reported as helping the most for this age group were (a) “I try to calm myself down” and (b) “I try to feel better by spending time with others, like family, grownups or friends.” One item never reported by the older siblings as helping was “I blame someone else for causing the problem.”

(b) Gender. The content analysis indicated that the two items used most often by girls were (a) “I try to fix the problem by thinking of answers” and (b) “I try to feel better by spending time with others, like family, grownups, or friends.” Two items were reported as being used least often: (a) “I blame myself for causing the problem” and (b) “I blamed someone else for causing the problem.” Girls reported that “I stay by myself” was the most helpful coping strategy. The least helpful strategy for girls was “I wish the problem had never happened.” According to the content analysis, boys had a different approach than girls, and the item used most often was “I wish the problem had never happened.” Coping strategies that boys reported using least often were (a) “I just try to forget it” and (b) “I do something like watch TV or play a game to forget it.” The item reported as being most helpful for boys was “I try to feel better by spending time with others, like family, grownups, or friends,” whereas “I yelled, screamed or got mad” was never used as a strategy.
Table 2

Mean Scores and Standard Deviations for KIDCOPE Measure

<table>
<thead>
<tr>
<th>Overall ratings</th>
<th>Overall</th>
<th>8-9 years</th>
<th>10-12 years</th>
<th>Boys</th>
<th>Girls</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you do this?</td>
<td>0.68 (0.13)</td>
<td>0.70 (0.21)</td>
<td>0.65 (0.13)</td>
<td>0.63 (0.19)</td>
<td>0.73 (1.34)</td>
</tr>
<tr>
<td>How much does it help?</td>
<td>1.14 (0.43)</td>
<td>1.09 (0.46)</td>
<td>1.09 (0.46)</td>
<td>0.92 (0.54)</td>
<td>1.34 (0.43)</td>
</tr>
</tbody>
</table>

Discussion

Our findings yielded significant information on sibling stressors, uplifts, coping style, and on the family coping style in the 12 families who participated. Given the small sample that precluded quantitative analyses, the findings of the content analysis were refined with qualitative follow-up data from parents.

Child Perceptions of Life with a Sibling with Special Needs

Based on the Sibling Daily Hassles and Uplifts Scale, 7/12 children reported that their sibling with special needs “always” responded negatively by crying or yelling when he/she did not want to do something. This behaviour may be linked to the item children reported as most stressful, namely being embarrassed by their sibling when friends came to their home. This kind of embarrassment may also extend into other public situations, as the qualitative data supplied by parents suggests. One parent’s description of the tantrums of the child with special needs and the reactions of his siblings offers important insight:

The girls find it very difficult when (my child with special needs) tantrums in public. One day, we decided to go shopping at Sears before going to a movie. (Child with special needs) was dropping, shrieking, and hitting people as they passed him (on the floor). I could not pick him up and carry him out because he was too heavy... The girls were humiliated and did not want to go to a movie anymore... The remainder of the evening, the girls were quite upset, and embarrassed (Parent 1, female sibling, age 10).

Other parents specified embarrassment as being linked to friends, as well as to public situations—a finding supported by the literature. Specifically, our findings are in line with those of Grossman (1972), Pit-Ten Cate and Loots (2000), and Powell and Gallagher (1993) who all reported that individuals with siblings having a disability reported some emotional discomfort. This discomfort was sometimes reflected by the typically-developing sibling’s feelings of shame, denial, or ambivalence about how to balance the needs of his/her sibling with special needs with his/her own peer relationships.

Interestingly, siblings in this study reported experiencing more frequent daily uplifts than hassles, and more intense feelings associated with the uplifts compared to hassles. Qualitative
data confirmed that positive daily events were universal among the typically-developing children, regardless of age or gender. Parents described their children as displaying love for their sibling with special needs: “Both of our sons love their sister very much. They both encourage her and revel in her accomplishments” (Parent 2, male sibling, age 9). Pit-Ten Cate and Loots (2000) also reported that children identified many positive experiences associated with having a sibling with a physical disability. As demonstrated by Giallo and Gavidia-Payne (2006), siblings’ daily uplifts were significant positive predictors of sibling prosocial behavior. Taken together, these findings suggest that there may be benefits for children who have a sibling with a disability.

Older and younger children appeared to have some differences in the issues they found most stressful. The particular issues the younger children found most stressful coincided with Lazarus and Folkman’s (1984) primary appraisal theory of the significance of events, which includes consideration of ego involvement. That is, the 8- and 9-year-old children reported daily hassles that directly involved themselves as most stressful (i.e., being embarrassed by their sibling, and not being able to do what they wanted because they were interrupted by their sibling). In contrast, consider the items the 10- to 12-year-old children found most stressful: “when my brother/sister with a disability cries, screams or yells when he/she doesn’t want to do something,” “when my brother/sister with a disability is sick or hurt,” and “when people do not understand about my brother/sister’s disability.” Each of these items includes a consideration of others in the appraisal, while younger children’s items were more self-focused. Although our findings are based on a small sample, they tentatively suggest developmental differences in stress appraisal similar to Sheets et al.’s (1996) report of developmental differences between younger and older school-age children experiencing divorce. These authors reported that children’s concepts of the self became differentiated with development; older children were more likely to think about events in more abstract ways. Qualitative parent data supports the above interpretation, for example, one comment from a parent of a younger sibling demonstrated the sensitivity of younger children to differential parental treatment:

(Sibling) sometimes expects us to treat her brother the same way we discipline her and when we fail to—for whatever reason—she gets angry and starts to resent him...there is often stress surrounding rules. She often expects all rules to apply to them equally. At times, more energy is devoted to her brother (Parent 6, female sibling, age 8).

Subtle gender differences were noted as well. The higher intensity ratings for boys on their daily hassles, coupled with the lower intensity ratings for daily uplifts, may possibly suggest that boys are more sensitive than girls to stress associated with their sibling with special needs. The literature presents conflicting information, with some studies finding that females are more affected (Cuskelly & Gunn, 1993) and others reporting that males are most affected (Grossman, 1972). Clearly this is an issue that requires further study.

Wishful thinking emerged as a common coping strategy for all siblings (92% of the sample), a finding demonstrated in other studies (Donaldson, Prinstein, Danovsky, & Spirito, 2000; Ross & Cuskelly, 2006). Boys and younger children also reported using this strategy most frequently. This method of coping focuses on controlling the emotional aspects of stress appraisal, rather than being a problem-focused method. Sorgen and Manne (2002) demonstrated that for children coping with cancer, emotion-focused coping strategies were linked to lower appraisals of control, whereas problem-focused strategies were associated with higher appraisals of control. In line with Bandura’s theory of self-efficacy (1977), younger children may perceive less personal control than older children or adults. We also note that all children reported using problem-
solving and social support strategies to cope with their daily hassles. Our findings suggest that children were facing, rather than avoiding, their stress. Since the least commonly used strategies were distraction or trying to forget about the problem, this may indicate that siblings of children with special needs may become immune to the disturbances caused by their sibling. One parent offered some insight into this possibility: “(Siblings) have grown so used to (child with special needs) noise that not even a fire alarm at night wakes them up” (Parent 11, female sibling, age 12).

An interesting difference was noted between the younger and older children’s coping strategies. The strategy used the least by younger children was keeping quiet about the problem, whereas older children reported using this strategy most often. Older children may also feel an increased responsibility to deal with their problems themselves, rather than relying on parents. Perhaps the older children’s additional experience may be related to their understanding that the disability was not something that could be fixed; certainly this speculation requires further study.

Girls and boys also seemed to demonstrate different coping methods: Girls reported using active problem-solving and social support techniques the most frequently, whereas boys reported using wishful thinking most often. Pit-Ten Cate and Loots (2000) also found that sisters of children with physical disabilities actively tried to solve their problems, rather than tolerating them. In the present study, boys reported that social support techniques helped the most, whereas girls reported that staying alone helped the most. The contradictions between coping strategies used the most and those that helped the most between genders are noted. Further investigation into why siblings use particular strategies is warranted to obtain a deeper understanding of the cognitive processes associated with their choices.

Parents’ Perceptions of Family Coping Styles

Based on parental reports, results suggest that families might be relying on their internal capacities to cope with the stress of having a child with special needs. The most often used strategy of “accepting stressful events as a fact of life” reported by all families reflects a direct, realistic way of approaching stress. One parent commented: “It is very hard to accept what life throws at us. Nevertheless, we still have to accept. There is no other way” (Parent 3). Another parent affirmed: “We have come to the conclusion that stress will always be a part of our life. We always try to solve one problem and to be ready to incur the next problem that should arise” (Family 5). Gold (1993) argued that this kind of attitude, especially when displayed by the mother, will positively impact on a typically-developing child’s acceptance of his/her sibling with special needs. Other parent comments indicated that acceptance of the disability and its accompanying stressors must precede any practical problem-solving. An active problem-solving strategy was the second most commonly reported by all parents (“facing the problem head on and trying to get a solution right away”). Perhaps parental acceptance influences the family’s ability to practically and realistically deal with their problems.

Duis and Summers (1997) reported that higher levels of family cohesion can act as a buffer against stress. Two such coping strategies used by all families to some degree included “showing that we are strong” and “knowing we have the power to solve major problems.” One parent commented: “As a team, we have worked together sometimes making decisions contrary to medical advice. But staying together and backing our decision with the belief that we have the power to get through our problems helps” (Family 2).
Frey et al. (1989) also reported that parents who used more problem-focused coping strategies had lower levels of psychological distress, whereas higher levels of distress were related to avoidance and wishful thinking strategies. Although the younger children in the present study frequently reported using wishful thinking strategies, parental modeling of positive strategies may be associated with more positive coping as their children develop. Certainly, this speculation requires further study. Interestingly, families infrequently used family support strategies. Parent comments indicated that a lack of understanding from those outside of the immediate family was the reason why relatives were not sought out for advice. One parent described using extended family to provide practical assistance (e.g., babysitting), rather than for advice or comfort.

Comparisons between family and child responses indicated that both siblings and families reported facing and accepting their stressors rather than being passive or avoiding them. The two least commonly used coping strategies reported by siblings were “I just try to forget it” and “I do something like watch TV or play a game to forget it.” With all parents using the strategy of “facing the problem head on and trying to get a solution right away” to some degree, it is possible that some children avoided using distraction and forgetting about their problems in response to their parent’s direct approaches. Whether or not an association exists between parent and child coping strategies, one parent’s comment demonstrates an active attempt to impart knowledge: “That’s what we teach our kids—be prepared because things happen unexpectedly and we can’t let it drag us down” (Family 3). All children also utilized problem-solving strategies, similar to parental reports; however, children may have used support strategies more than their parents did. Whereas most parents avoided spiritual and extended family supports, children reported that spending time with others (e.g., family, adults, and friends) was the most helpful strategy.

Limitations and Conclusions

In sum, these families demonstrated high levels of adaptation in response to their family stress. Yet, the small sample size, limited variability in terms of religion, ethnicity, SES, and a lack of a comparison group indicate results may not be generalizable. Also, it may be that because these families had been dealing with the stress of childhood disability for several years (range of 3–14 years), their adaptation may reflect that they had the time to develop positive coping responses and find appropriate resources. Families may require more resources and support in the early phase of the diagnosis of a disability. It is likely that in these early stages siblings experience different types of stressors, perhaps more frequently and more intensely. Siblings should continue to be interviewed at different ages and stages to ascertain a holistic view of their experience and to chart changes over time.

During our interviews, siblings often demonstrated excitement and pride when given the opportunity to discuss their experiences with a sibling with special needs, which is an encouraging sign for family dynamics. Employing a self-report interview method not only yields more accurate information, but it may also provide opportunities for children to express self-esteem and confidence. The findings indicate that children’s concerns should be considered when designing support and resources for these families. Specifically, children should be asked about their motivation for choosing their particular coping strategies and, perhaps, if warranted, be guided toward developing more positive strategies. Particular stressors can be pinpointed from sibling self-reports, and the growing number of sibling support groups can incorporate these issues into their curriculum.
In conclusion, our findings suggest that many families continue to thrive and find strength from their unique situations. Further discussions that include the typically-developing sibling’s perspective will serve to develop positive coping strategies for families and encourage the family members to use each other as resources and sources of support. Families themselves have proven to be strong resources, which lends a great deal of support to the idea of peer family support groups, where families whose children are further along in the disability lifespan can mentor families in the earlier stages. This idea can work effectively with siblings, providing confidence and leadership skills to older siblings, while mentoring and educating a younger child experiencing similar circumstances. By including all family members in the study of childhood disability, more comprehensive information and more effective resources can be designed for these families.

References


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This study was supported by a grant from the Social Sciences and Humanities Research Council of Canada to the second author. We wish to thank the families who participated.