

## Stresses and Coping Strategies of Chinese Families with Children with Autism and Other Developmental Disabilities

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**Abstract** Data from 368 families of children with autism and other developmental disabilities in the People's Republic of China were gathered to understand the stresses that families experience and the coping strategies they employ. Chinese families of children with developmental disabilities perceived high levels of stress related to pessimism, child characteristics, and parent and family problems. Regarding coping strategies, acceptance, active coping, positive reinterpretation and growth, suppression of competing activities, and planning were the most frequently employed coping strategies. Parents of children with autism experienced more stress and used planning as a coping strategy to a greater degree than parents of children with other developmental disabilities. The implications and limitations of these findings are discussed.

**Keywords** Family stress · Family coping · China · Autism

Research suggests that families of children with developmental disabilities frequently experience high levels of stress (e.g. Abbeduto et al. 2004; Dumas et al. 1991; Rodrigue et al. 1990; Warfield 2005). For example, mothers of children with developmental disabilities reported significantly higher levels of stress and assigned more negative child characteristics than mothers of children without disabilities (Emerson 2003; Neece and Baker 2008). Among families of children with developmental disabilities,

mothers of children with autism reported higher levels of stress and lower levels of parenting competency than mothers of children with Down syndrome (Hastings et al. 2005; Hoffman et al. 2009; Sanders and Morgan 1997).

Although research on Chinese families of children with developmental disabilities is limited, studies report similar findings to those related to western families. Huang et al. (1998) surveyed 135 mothers of children with mental retardation in Shanghai. Huang et al. suggest that there were more negative attitudes toward persons with severe intellectual disabilities than toward persons with mild intellectual disabilities. Additionally the increased negative attitudes of neighbors may contribute to increased levels of maternal stress. Furthermore, it is generally recognized that in Chinese society, parents attach high value to the academic achievement of their children. Since children with more severe intellectual disability face greater obstacle in the fulfillment of family expectations related to academic achievement than their peers with less significant disabilities; thus mothers of children with severe intellectual disabilities maybe experience higher levels of stress than mothers of children with milder disabilities. According to Huang and colleagues, in general the stress level of Chinese mothers of children with intellectual disability was generally higher than the stress level reported in studies of parents of children with autism in the United States, as measured by the Parenting Stress Index (see Abidin 1995). In the United States, the mean Parenting Stress Index (PSI) score for parents of children with developmental disabilities was 254. In contrast, the mean PSI score for Chinese mothers in this study was 282. Abidin (1995) suggested that parents whose scores on the PSI are over 260 could benefit from professional assistance. It was found that 75% of respondents in the Huang et al. study scored 260 and above on the PSI.

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McCabe (2008) examined the experiences of 78 parents (70 mothers, 8 fathers) of children with autism regarding their personal experiences and the experiences of their families in terms of having a child with autism. Using a combination of questionnaires and follow-up interviews, McCabe reported that Chinese families experienced shock and confusion in relation to having a child diagnosed with autism. Because parents' hopes and expectations for their one and only child were so high—based on the fact that families in China tended to have only one child, accepting the autism diagnosis becomes extremely difficult. Therefore, the stress level was extremely high as well. Some differences were also noted between mothers and fathers, with mothers in most cases being the primary caregiver. Mothers tended to report increased stress, anxiety, and depression. Father tended to become less involved and somewhat more distant. McCabe also reported that having a child with autism significantly impacted the relationship between spouses in both positive and negative ways.

Family research in western countries supports a negative correlation between stress levels in families of children with disabilities and their social supports and coping skills. In other words, in families of children with disabilities, increases in helpful coping strategies and available supports tends to be associated with decreases in reported levels of stress (Hastings et al. 2005; Weiss 2002). Hastings et al. (2005) reported four key coping dimensions relevant to raising a child with autism—avoidance coping, problem-focused coping, positive coping, and religious coping. Hastings et al. suggest that the use of positive reframing of potentially traumatic and stressful events may be one of the only effective coping strategies available to families under extreme conditions. Also, mothers and fathers may adopt different coping strategies.

The family counseling and therapy literature describe similar trends. Blackledge and Hayes (2006), for example, explored the use of Acceptance and Commitment Therapy to address the family psychological needs of parents of children with autism. Acceptance and Commitment Therapy (ACT) is grounded in the principle that reframing might be one of the most effective coping tools of families. In other words, in ACT a therapist might work with a family to reframe a perceived problem as an opportunity for growth instead. A family therapist would use ACT to challenge content of difficult thoughts and emotional experiences.

Acceptance and Commitment Therapy might be particularly well suited for working with Chinese families of students with autism and other developmental disabilities, a family therapist might emphasize the clarification of personally held values and goals as the aforementioned dynamics are occurring with family therapy sessions. Qian

et al. (2002) suggest that this type of emphasis in a therapy session would help “incorporate the philosophical ideas of unity of the universe and the need for harmony” (p. 60) present in Taoist philosophy and perhaps enable a greater acceptance of family therapy in Chinese families.

Yet to date, there is no evidence in the professional literature that there have been any family therapy studies conducted in China on the use of ACT and “[s]ocial stigma and shame surrounding help-seeking behavior are still quite prevalent in China” (Qian et al. 2002, p. 52).

Due to the general lack of understanding of autism and other developmental disabilities in the People's Republic of China and the Chinese etiological beliefs regarding disabilities (Wang 2009), many families may be resistant to seeking out the services of a therapist. According to this etiological belief, the existence of disability is a punishment for an ancestor's misbehavior or the disability is due the current family's disregard of their obligation to honor their ancestors (Chan and Lee 2004; Deng et al. 2001; McCabe 2007). Additionally, families with children with severe disabilities reported a significant lack of trained professionals to support families and children (Wang and Michaels 2009).

Based on the existing literature with Chinese families with children with developmental disabilities, avoidance appears to be the most dominant coping strategy employed. Interestingly, the majority of this research has been conducted in Hong Kong rather than mainland China. Lam and Mackenzie (2002) explored the experiences of 18 mothers in Hong Kong who had children with Down syndrome. They concluded that the presence of Down syndrome was a significant, ongoing source of stress and that the nature and intensity of this increased stress changes over time. Mothers employed different coping strategies during different family life cycles. When children were young (in this case, between birth and six months), mothers attempted to hide the disability from others to maintain face. Therefore, their coping resources tended to be limited as typically the husband was the only one who knew and who could therefore potentially provide support to the mother. At this early stage, coping strategies tended to be emotion-focused and avoidance was particularly evident. As children grew older, mothers tended to become more self-reliance and began to seek social support from others; however, avoidance still remained one of the most frequently employed coping strategies.

Shek and Tsang (1993) evaluated the coping strategies of 381 parents of preschool children with intellectual disability in Hong Kong and reported that a significant proportion of the parents tended to use internal coping strategies to deal with stress and problems arising from taking care of their children with intellectual disabilities (e.g. “face the problem and devise solution,” “forbear and

remain calm”). These researchers reported that approximately half of the families in their sample never sought assistance from friends, relatives, parents, or in-laws; about a third of this group also had never sought support from professionals in developmental disabilities (e.g., teachers, therapists, doctors).

Mak and Ho (2007) examined the effects of three different coping strategies (i.e. problem-focused, emotion-focused, and relationship-focused coping) on positive and negative caregiver perceptions of children with intellectual disability in Hong Kong. Relationship-focused coping aims at managing, regulating, and preserving relationships during stressful periods. Mak and Ho suggested that since relationship harmony is an important aspect of Chinese culture and the mother–child relationship is recognized as one of the primary relationships, it is logical that relationship-focused coping takes on a significant role in shaping mothers’ perceptions of the care-giving process. Mak and Ho further suggest that because of the strong influence of interpersonal relatedness in Chinese culture, relationship-focused coping for Chinese caregivers plays an essential role in building and maintaining relationships within the family. Caregivers who use relationship-focused coping strategies tended to (a) have greater appreciation for their role as caregiver, (b) experience personal growth along the way, and (c) report less sense of burden and negative feelings toward their children.

The purpose of the current descriptive study was to further the knowledge on Chinese families of children with autism and other developmental disabilities. Specifically this study gathered empirical data about families from the People’s Republic of China in relation to parenting and raising a child with developmental disabilities in order to better understand the types of (a) stresses that families experience, and (b) the coping strategies that families’ utilize.<sup>1</sup>

Four research questions guided this study:

1. What are the perceived stresses experienced by parents of children with developmental disabilities in China?
2. What types of coping strategies are utilized by parents of children with developmental disabilities in China?
3. Are there differences between stresses and coping strategies of mothers and fathers?
4. Are there differences among parents in terms of stresses and coping strategies associated with the disability of the child?

<sup>1</sup> This was part of a larger study, which also gathered data about perceived needs and supports of families of children with autism and other developmental disabilities in the People’s Republic of China. These data are reported separately (see Wang & Michaels, 2009).

## Method

### Participants

In total 465 survey packages were distributed and 368 packages were completed and returned, for an overall response rate of approximately 79.14%. Participation was voluntary and anonymous. Potential participants were informed that returning the completed information packet indicated their informed consent. Potential participants were also offered a small remuneration for completing the information package (i.e., 30 Yuan, approximately \$4.38). In the majority of cases the informational packet was completed and returned by either the mother or father of the child with developmental disabilities, however in some cases the packet was completed and returned by a grandparent.

### Recruitment Procedures

Participants were recruited from two cities in China, Beijing and Shenyang through three different recruitment strategies.

#### *Strategy 1: Recruitment at Autism Conference in Beijing*

The first of the three recruitment strategies was to recruit participants at an international conference on autism that was held in Beijing. One hundred copies of the information packet were distributed to families at this conference. These respondents were mainly from the Beijing metropolitan area. Forty-seven questionnaires were returned. The approximate response rate for this strategy was 47%.

#### *Strategy 2: Recruitment at a Private School for Children with Autism in Beijing*

The second strategy was to recruit parents directly from a private school for children with autism in Beijing. Thirty-five surveys were sent out to parents and 24 were returned. Approximate response rate for this strategy was 69%.

#### *Strategy 3: Recruitment at Schools for Children with Intellectual Disabilities in Shenyang*

Lastly, parents were recruited from five publicly funded special schools for children with intellectual disabilities in Shenyang. While the five public schools in Shenyang mainly served students with intellectual disabilities, these schools also served a limited number of individuals with autism, with physical disabilities, and with other developmental disabilities. Informational packets were sent out to the parents of the 330 students across the five schools with

a total of 297 packets returned. The response rate for this recruitment strategy was approximately 90%.

### Disability Categorizing Procedures

The term, “*developmental disabilities*,” [i.e., severe chronic conditions that are due to mental and/or physical impairments with an age of onset prior to age 22 (Center for Disease Control and Prevention 2004)] is not recognized or used in official documents or by the general public in China. “*Intellectual disabilities/Mental Retardation*”, “*physical disabilities*”, and “*autism*” are terms that are used in China and are subsumed in our use of the term developmental disabilities. The Chinese diagnostic criteria for intellectual disabilities/mental retardation, physical disabilities and autism are comparable to the western practices.

For purposes of this study all disability determinations were based solely on the self-report of responding family members to an open-ended question about “your child’s disability.” Information about disability was collapsed into four categories aligned with western disability classification schema. The four categories were (a) autism, (b) mental retardation, (c) physical disabilities, and (d) other developmental disabilities. The category “other developmental disability” was used when a respondent wrote in “*buxiang*” (unknown), failed to provide an answer at all, or simply provided general information about a child’s cognitive and behavioral difficulties.

### Instrumentation

Respondents were asked to fill out an informational packet that consisted of six items: (a) a brief description of the study and a statement of informed consent, (b) a brief demographic information sheet, (c) an adapted version of the *Family Needs Survey* (Bailey and Simeonsson 1988, 1990), (d) an adapted version of the *Family Support Scale* (Dunst et al. 1988); (e) an adapted version of the *Questionnaire on Resources and Stress* (Friedrich et al. 1983); and (f) an adapted version of the *COPE Inventory* (Carver et al. 1989).<sup>2</sup>

#### *Demographic Information Sheet*

The brief demographic information sheet was created specifically for this study and asked respondents to provide information in three areas: information about themselves (e.g., role in the family, gender); information about the

family of the child with disabilities (e.g., age of each parent, occupations, level of education, monthly income level); and information about the child with a disability (e.g., age, gender, disability).

#### *Questionnaire on Resources and Stress*

The original Questionnaire on Resources and Stress (QRS) was a 285-item true–false instrument that was developed to measure the impact of a child with developmental disabilities or chronic conditions on other family members (Holroyd 1974). However, the Questionnaire on Resources and Stress (Friedrich, short form: QRS-F) is the most frequently used short form to study stress in families of children with disabilities in the developed world (Glidden and Floyd 1997). The QRS-F has 52 items that measures four subcomponents of parental perceptions: *parent and family problems* (i.e., perception of problems for themselves, other family members, or the family as a whole), *pessimism* (i.e., immediate and future pessimism about the child’s prospects of achieving self-sufficiency), *child characteristics* (i.e., perception of the specific behavioral or attitudinal difficulties presented by the child), and *physical incapacities* (i.e., perceptions of limitations in the child’s physical abilities and self-help skills). Friedrich et al. (1983) report an overall alpha reliability coefficient of .93 for QRS-F. All QRS-F items were translated into Chinese by the first author. In some cases, minor modifications were made to wording in order to preserve overall meaning.

#### *COPE Inventory*

The COPE Inventory was developed by Carver et al. (1989) to assess a broad range of coping responses or strategies. The inventory consists of 60 items divided into 15 subscales, (a) positive reinterpretation and growth, (b) mental disengagement, (c) focus on and venting of emotions, (d) use of instrumental social support, (e) active coping, (f) denial, (g) religious coping, (h) humor, (i) behavioral disengagement, (j) restraint, (k) use of emotional social support, (l) substance use, (m) acceptance, (n) suppression of competing activities, and (o) planning. The items are rated on a 4-point scale with values identified as 1, “*I usually don’t do this at all;*” 2, “*I usually do this a little bit;*” 3, “*I usually do this a medium amount;*” and 4, “*I usually do this a lot.*” Each subscale consists of 4 items. The values of each subscale are computed by summing all 4 items listed with no reversals of coding. In other words, the possible values for each subscale range from 4 to 16. According to Carver et al. (1989), the internal consistency of the COPE scales was generally high (>.62) with the exception of one subscale, mental disengagement. The test–retest reliability reported by Carver et al. (1989)

<sup>2</sup> Analyses associated with the *Family Needs Survey* and the *Family Support Scale*, are not included in this article. They are reported in Wang and Michaels (2009).

suggests that self-reports of coping styles are relatively stable. Again, all COPE items were translated into Chinese by the first author with some minor modifications to wording in order to preserve overall meaning.

### Data Analysis

All data were entered into a SPSS version 11.5 database (SPSS, Inc. 2001) by a graduate research assistant who was fluent in Chinese. Fidelity of data entry was checked by the first author in terms of data entry accuracy (i.e., entering correct values) and preserving meaning (i.e., translating from Chinese into English). Percentages were calculated for all nominal level variables, medians and ranges were calculated for all ordinal level variables, and means and standard deviations were calculated for all interval level variables. Differences between nominal and ordinal variables (i.e., subscale scores on the QRS-F) were analyzed using Mann–Whitney tests for comparisons between mothers' and fathers and the Kruskal–Wallis test for comparisons across categories of child's disability. Differences between nominal and interval variables (i.e., subscale scores on the COPE Inventory) were analyzed using the independent sample *t*-test for comparisons between mothers' and fathers and the one-way analysis of variance (ANOVA) test for comparisons across categories of child's disability. Based on the exploratory nature of this study, only Kruskal–Wallis tests and ANOVAs with alpha levels of significance of  $p < .01$ , were followed-up by post-hoc analyses. Statistically significant Kruskal–Wallis tests were followed up with Mann–Whitney tests [with *Bonferroni* correction to control for Type 1 errors (Field 2009)] and statistically significant ANOVAs were followed up with Scheffe tests [a conservative post-hoc approach to minimize potential Type 1 errors (Argyrous 2005)]. Alpha level for all post-hoc Mann–Whitney and Scheffe tests was set at  $p < .05$ .

## Results

### Participants

A total of 368 information packets were completed and returned, for an overall response rate of about 79%. The 368 information packets that were returned represented responses from 368 separate families of children with autism and developmental disabilities. In other words, in no cases did both parents complete separate packets for the same child or did someone who completed the packet at the conference on autism (recruitment strategy 1) also complete a packet at a school either in Beijing (recruitment strategy 2) or Shenyang (recruitment strategy 3).

Approximately 93% ( $n = 340$ ) of respondents were the parent of a child with disabilities (mothers'  $n = 216$ , 59.2%; fathers'  $n = 124$ , 34.0%). The remaining 6% of respondents ( $n = 22$ ) were a grandparent of a child with disabilities (grandmothers'  $n = 9$ , 2.4%; grandfathers'  $n = 13$ , 3.6%).

On average, parents were in the late 30 s or early 40 s (mothers' mean age 38.70 years,  $SD = 5.52$ ; fathers' mean age 40.28 years,  $SD = 5.61$ ). In terms of level of education, parents had completed either middle school or high school (mothers' and fathers' education less than or equal to high school, approximately 60% each). The unemployment rate for fathers was reported to be approximately 30% and for mothers about 40%. Approximately 88% of the families had a monthly combined income of 5000 Yuans or less (less than 650 US dollars), which represents the working class in China.

In terms of the children with disabilities approximately 70% were male ( $n = 258$ ) and 30% were female ( $n = 108$ ). The mean child age was 11 years old ( $SD = 4.17$  years). In terms of disability classification or diagnosis, approximately 37% of children were identified as children with autism ( $n = 137$ ), about 37% were identified as children with mental retardation ( $n = 135$ ), 12% were identified as children with physical disabilities ( $n = 44$ ), and about 14% of the children were identified as children with other types of developmental disabilities ( $n = 52$ ).

### Perceived Stress

Research question one focused on the perceived stresses experienced by parents of children with autism and developmental disabilities in China. Table 1 presents the medians and ranges for the four subscales of the QRS-F (Friedrich et al. 1983). All items were scored with either 1 = True, or 0 = False. The items within each stress factor were summed and then divided by the total number of items within that stress factor to allow for comparisons across stress factors. The data in Table 1 indicate that generally speaking, Chinese parents of children with disabilities perceive high levels of stress in the area of *Pessimism* (Median = .6364, range = 1.00); *Parent and Family Problems* (Median = .5500, range = .90); and *Child Characteristics* (Median = .5333, range = 2.20).

### Types of Coping Strategies

The second research question focused on the types of coping strategies utilized by families of children with autism and developmental disabilities in China. Table 2 presents the means and standard deviations for the 15 subscales of the COPE Inventory (Carver et al. 1989). The

**Table 1** Overall medians and ranges on the Questionnaire on Resources and Stress Subscales

Family stress area	N	Median <sup>a</sup>	Range
Parent and family problems	321	.5500	.90
Pessimism	344	.6364	1.00
Child characteristics	320	.5333	2.20
Physical incapacitation	350	.1667	.83

<sup>a</sup> All items were scored with either 1 = “True,” or 0 = “False.” The items within each stress area were summed and then divided by the total number of items within that stress area to allow for comparisons across stress areas

data in Table 2 suggest that the five most frequently reported coping strategies included: *Acceptance* ( $M = 12.97$ ,  $SD = 2.96$ ); *Active Coping* ( $M = 12.85$ ,  $SD = 2.81$ ); *Positive Reinterpretation and Growth* ( $M = 12.48$ ,  $SD = 2.51$ ); *Suppression of Competing Activities* ( $M = 12.16$ ,  $SD = 2.90$ ); and *Planning* ( $M = 12.11$ ,  $SD = 2.84$ ).

#### Differences in Perceived Stress and Coping Strategies for Mothers and Fathers

The third research question focused on identifying any potential differences between mothers and fathers in relation to either perceived stress or utilization of coping

**Table 2** Overall means and standard deviations on the cope inventory

Family coping strategy area	N	M <sup>a</sup>	SD
Positive reinterpretation and growth	304	12.477	2.51
Mental disengagement	344	9.477	2.46
Focus on and venting of emotions	330	7.885	2.13
Use of instrumental social support	351	11.385	2.85
Active coping	340	12.850	2.81
Denial	350	8.103	2.74
Religious coping	345	8.484	3.86
Humor	344	7.317	2.73
Behavioral disengagement	343	8.997	2.77
Restraint	342	11.337	2.82
Use of emotional social support	352	10.571	2.98
Substance use	343	5.292	2.47
Acceptance	344	12.968	2.96
Suppression of competing activities	356	12.155	2.90
Planning	343	12.114	2.84

<sup>a</sup> Items scored on a 4-point scale (1 = “I usually don’t do this at all,” 2 = “I usually do this a little bit,” 3 = “I usually do this a medium amount,” and 4 = “I usually do this a lot.” Each coping strategy area consisted of 4 items. Thus scores within a given area could range from a total of 4–16

**Table 3** Mann–Whitney test comparisons for mothers and fathers on the Questionnaire on Resources and Stress subscales

Stress area	Mean ranks and sum of ranks				U-value
	Fathers		Mothers		
Parent and family problems	135.24	14335.5	158.11	30514.5	8864.5*
Pessimism	162.39	19161.5	159.40	32198.5	11695.5
Child characteristics	146.57	15830.0	152.71	29320.0	9944.0
Physical incapacitation	162.26	19306.5	163.34	33668.5	12166.5

\*  $p < .05$

strategies. Only participants who identified themselves as mothers ( $n = 216$ ) or fathers ( $n = 124$ ) were included in the independent  $t$ -test analyses associated with this research question.

Table 3 presents the results for the Mann–Whitney test comparisons associated with the QRS-F. In addition, Table 3 provides the mean ranks and sum ranks for mothers and fathers on all subscales. In terms of the Mann–Whitney tests for mothers and fathers on the QRS-F, only one subscale, *Parent and Family Problems* ( $U = 8864.5$ ,  $p < .05$ ) was statistically significant. Mothers (Median Rank = 158.11) appeared to perceive more parent and family related problems than fathers (Median Rank = 135.24).

Table 4 presents the means, standard deviations, and differences for mothers and fathers on all COPE Inventory subscales. This table also presents the  $t$ -test values for comparisons between coping styles of mothers and fathers. In terms of the independent  $t$ -tests for mothers and fathers on the COPE Inventory, three subscales comparisons were statistically significant: *Focus on and Venting of Emotions* ( $t = -3.663$ ,  $p < .01$ ); *Substance Use* ( $t = 4.267$ ,  $p < .01$ ); and *Suppression of Competing Activities* ( $t = -2.175$ ,  $p < .05$ ). Mothers ( $M = 8.21$ ,  $SD = 2.13$ ) were more likely to focus on and vent their emotions than fathers ( $M = 7.33$ ,  $SD = 1.87$ ). Mothers were also more likely to suppress competing activities than fathers (mothers  $M = 12.35$ ,  $SD = 3.00$ ; fathers  $M = 11.63$ ,  $SD = 2.73$ ). On the other hand, fathers ( $M = 6.06$ ,  $SD = 3.04$ ) tended to be more prone to use substance as a method of coping than mothers ( $M = 4.86$ ,  $SD = 1.99$ ).

#### Differences in Perceived Stress and Coping Strategies by Child’s Disability

The final research question focused on differences among families in terms of stresses and coping strategies associated with the disability of the child—autism, mental

**Table 4** Independent *T*-test comparisons for mothers and fathers on the cope inventory

Family coping strategy area	Mean and standard deviation			<i>t</i> -value
	Fathers	Mothers	Difference <sup>a</sup>	
Positive reinterpretation and growth	12.26 (2.35)	12.58 (2.62)	-.3169	-1.024
Mental disengagement	9.21 (2.36)	9.65 (2.47)	-.4365	-1.536
Focus on and venting of emotions	7.33 (1.87)	8.21 (2.13)	-.8750	-3.663**
Use of instrumental social support	11.38 (2.74)	11.31 (2.93)	.0611	.185
Active coping	12.58 (2.93)	12.94 (2.80)	-.3618	-1.084
Denial	8.29 (2.79)	7.89 (2.64)	.4058	1.307
Religious coping	8.19 (3.79)	8.63 (3.83)	-.4369	-.988
Humor	7.54 (2.75)	7.14 (2.71)	.4038	1.278
Behavioral disengagement	8.75 (2.64)	9.10 (2.80)	-.3458	-1.075
Restraint	11.14 (2.82)	11.41 (2.82)	-.2753	-.838
Use of emotional social support	10.13 (3.06)	10.69 (2.93)	-.5564	-1.617
Substance use	6.06 (3.04)	4.86 (1.99)	1.2036	4.267**
Acceptance	12.60 (3.24)	13.11 (2.83)	-.5055	-1.446
Suppression of competing activities	11.63 (2.73)	12.35 (3.00)	-.7243	-2.175*
Planning	11.95 (3.03)	12.13 (2.79)	-.1763	-.526

<sup>a</sup> Difference equals the difference between fathers' and mothers' mean

\* *p* < .05

\*\* *p* < .01

**Table 5** Stress area median scores, number of respondent above and below median, and Kruskal–Wallis analysis for the questionnaire on resources and stress subscales by child's disability

Family stress area	Overall median	Child's disability								Kruskal–Wallis <i>H</i> ( <i>df</i> = 3)
		ASD		MR		PD		Other		
		> Mdn	≤Mdn	>Mdn	≤Mdn	>Mdn	≤Mdn	>Mdn	≤Mdn	
Parent and family problems	.5500	67	54	47	70	17	22	24	20	12.938**
Pessimism	.6364	48	82	54	72	14	25	25	24	2.508
Child characteristics	.5333	81	38	47	70	10	28	20	26	52.951***
Physical incapacitation	.1667	37	90	25	105	10	32	9	42	5.275

\* *p* < .05, \*\* *p* < .01, \*\*\* *p* < .001

retardation, physical disabilities, or other developmental disability. Table 5 presents the results of the Kruskal–Wallis one-way analysis of variance tests for each stress factor of the QRS-F by child's disability. Table 6 presents similar information for the ANOVA tests associated with the COPE Inventory by the disability of the child. Table 6 also presents the COPE Inventory means and standard deviations by each of the four disability category (i.e., autism, mental retardation, physical disabilities, and other developmental disabilities).

In terms of the Kruskal–Wallis test for the stress areas of the QRS-F by child's disability, two areas were founded to be statistically significant: *Parent and Family Problems* (*H* = 12.938, *df* = 3, *p* < .05), and *Child Characteristics* (*H* = 52.951, *df* = 3, *p* < .001). Both stress areas were

followed up with post-hoc analyses using the Mann–Whitney test with suggested *Bonferroni* corrections to control for Type 1 errors across multiple post-hoc comparisons. Post-hoc testing for *Parent and Family Problems* suggested statistically significant differences between parents of children with autism and parents of children with mental retardation (Mann–Whitney *U* = 5219.0, *p* < .001). Post-hoc testing for *Child Characteristics* suggested significant differences between parents of children with autism and parents of children with mental retardation (Mann–Whitney *U* = 3689.5, *p* < .001); parents of children with autism and parents of children with physical disabilities (Mann–Whitney *U* = 901.5, *p* < .001), and parents of children with autism and parents who reported their child's disability as other (Mann–Whitney *U* = 1772.0, *p* < .001).

**Table 6** Group means, standard deviations, and ANOVA comparisons for the cope inventory by child's disability

Family coping strategy	Child's disability								ANOVA			
	ASD		MR		PD		Other		Sums of squares			
	<i>M</i>	SD	<i>M</i>	SD	<i>M</i>	SD	<i>M</i>	SD	Between groups	Within groups	<i>dF</i>	<i>F</i>
Positive reinterpretation and growth	12.81	2.54	12.30	2.66	12.73	1.74	11.85	2.55	33.907	1879.932	3, 300	1.804
Mental disengagement	9.69	2.41	9.36	2.45	9.26	2.27	9.42	2.80	9.288	2072.526	3, 340	.508
Focus on and venting of emotions	8.24	2.17	7.52	1.92	7.88	2.12	7.98	2.50	31.416	1466.208	3, 326	2.328
Use of instrumental social support	11.77	2.79	11.08	2.87	12.12	2.65	10.58	2.91	86.238	2764.839	3, 347	3.608*
Active coping	13.35	2.70	12.45	2.88	13.23	2.92	12.31	2.61	72.089	2599.261	3, 336	3.106*
Denial	7.16	2.49	8.65	2.77	8.63	3.04	8.60	2.44	175.604	2448.693	3, 346	8.271**
Religious coping	8.45	3.91	8.35	3.79	8.66	3.96	8.77	3.90	7.418	5106.745	3, 341	.165
Humor	6.89	2.70	7.67	2.67	7.70	3.15	7.22	2.49	45.051	2505.411	3, 340	2.038
Behavioral disengagement	8.25	2.49	9.30	2.85	9.46	3.12	9.73	2.51	117.220	2499.777	3, 339	5.299**
Restraint	11.76	2.64	11.02	2.82	11.88	2.61	10.58	3.26	74.530	2645.801	3, 338	3.174*
Use of emotional social support	10.45	2.81	10.43	3.08	11.62	3.16	10.38	2.85	52.518	3055.707	3, 348	1.994
Substance use	4.73	1.83	5.90	2.76	5.18	2.37	5.31	2.87	87.044	1995.802	3, 339	4.928**
Acceptance	13.32	2.92	12.30	2.30	13.56	2.47	13.24	3.13	89.133	2917.515	3, 340	3.462*
Suppression of competing activities	12.66	2.96	11.76	2.97	12.67	2.24	11.48	2.80	88.846	2887.657	3, 352	3.610*
Planning	12.67	2.57	11.52	3.08	12.81	2.33	11.57	2.92	118.939	2635.627	3, 339	5.099**

\*  $p < .05$ ; \*\*  $p < .01$ 

In terms of the ANOVA tests for the various subscales of the COPE Inventory by child's disability (Table 6), nine of the fifteen subscales were found to be statistically significant: *Use of Instrumental Social Support* ( $F = 3.608$ ,  $p < .05$ ); *Active Coping* ( $F = 3.11$ ,  $p < .05$ ); *Denial* ( $F = 8.27$ ,  $p < .01$ ); *Behavioral Disengagement* ( $F = 5.30$ ,  $p < .01$ ); *Restraint* ( $F = 3.17$ ,  $p < .05$ ); *Substance Use* ( $F = 4.93$ ,  $p < .01$ ); *Acceptance* ( $F = 3.46$ ,  $p < .05$ ); *Suppression of Competing Activities* ( $F = 3.61$ ,  $p < .05$ ); and *Planning* ( $F = 5.10$ ,  $p < .01$ ).

Based on the exploratory nature of this study, only the four subscales with ANOVA test significances at alpha less than .01 were followed up with post-hoc analyses. Post-hoc testing for the subscale *Denial* suggested significant differences between parents of children with autism and parents of children with mental retardation (mean difference =  $-1.4924$ ,  $p < .001$ ); parents of children with autism and parents of children with physical disabilities (mean difference =  $-1.4692$ ,  $p < .05$ ); and parents of children with autism and parents who reported their child's disability as other (mean difference =  $-1.4374$ ,  $p < .05$ ). In other words, parents of children with autism were less likely to use denial as a coping strategy than parents of children with other types of severe disabilities. Post-hoc testing for the subscale *Behavioral Disengagement* suggested significant differences between parents of children with autism and parents of children with mental retardation

(mean difference =  $-1.0489$ ,  $p < .05$ ) and parents of children with autism and parents who reported their child's disability as other (mean difference =  $-1.4867$ ,  $p < .05$ ).

It appears that parents of children with autism were less likely to use *behavioral disengagement* as a coping strategy when compared to parents of children with other types of severe disabilities. Post-hoc testing for the subscale *Substance Use* suggested significant differences only between parents of children with autism and parents of children with mental retardation (mean difference =  $-1.1694$ ,  $p < .01$ ), suggesting that parents of children with autism were less likely than parents of children with mental retardation to use substances as a coping strategy. Post-hoc testing for the subscale *Planning* suggested significant differences between parents of children with autism and parents of children with mental retardation (mean difference =  $1.1496$ ,  $p < .05$ ), indicating that parents of children with autism tended to use more planning as a coping strategy than did parents of children with mental retardation.

## Discussion

Data were reported from 368 separate families of children with autism and other developmental disabilities in the People's Republic of China. It is worthy to note that participants reported an unemployment rate for fathers of

approximately 30% and about 40% for mothers. Comparison data for the same year that these data were collected (2007) indicated only a 4% unemployment rate in most urban areas of China and about a 9% unemployment rate in rural areas (Central Intelligence Agency 2009). These differences may be in part due to the fact that some of the participants had given up their jobs and moved to the city to enable their children with autism or other developmental disabilities to receive educational services and supports. Also, a large portion of the sample was drawn from Shenyang (recruitment strategy 3), which is an economically struggling city.

In relation to income for a majority of the sample, approximately 88% reported a combined family income of less than 650 US dollars per month. This appears roughly equivalent to, or perhaps a tad lower than, the \$458 mean monthly income reported for individual earners in the comparison year (Central Intelligence Agency 2009).

With respect to the overall percentage of male children with disabilities (roughly 70%) among the families within this sample, perhaps this can be explained by the fact that approximately a third of the responding families were parents of children with autism. Current estimates of the number of male to female children with autism range between 3 to 1 and 4 to 1 and these gender differences are fairly consistent across ethnicities (Centers for Disease Control and Prevention 2009). Perhaps parents in China also experience greater pressure from their families and communities, and/or assign greater importance, to actively seek services for male children with developmental disabilities than female children; however, these speculations are beyond the scope of the data presented here.

Results indicate that at least for those families that participated in this study there were high levels of perceived stress in the areas of pessimism, child characteristics, and parent and family problems among families raising children with developmental disabilities in the People's Republic of China. Parents of children with autism seemed to perceive more stress than parents of children with mental retardation in the areas of parent and family problems, and child characteristics. Acceptance, active coping, positive reinterpretation and growth, suppression of competing activities, and planning were the five most frequently reported coping strategies. Although parents of children with autism appeared to experience more stress than parents of children with other disabilities, they were also more likely to use planning as a coping strategy.

Although the findings related to family stress were fairly consistent with levels of stress reported in research from western countries (Abbeduto et al. 2004; Emerson 2003; Hastings et al. 2005; Hoffman et al. 2009; Neece and Baker 2008; Warfield 2005), the Chinese families in this sample appear to be more pessimistic about their children's future

due to factors somewhat unique to the People's Republic of China (McCabe 2008; Wang and Michaels 2009), including: (a) the severe shortage of trained professionals and public educational placement for their children; (b) the added financial burden and related stress associated with paying for training and rehabilitative services; and (c) concerns regarding their children's futures as adults, especially after their (i.e., the parents) death. Additionally, as described in Wang and Michaels (2009), families expressed the need for knowledge regarding their children's disabilities and parenting skills, such as how to manage their children's challenging behaviors.

In reference to the aforementioned factors, our review of the literature supports the dearth of trained professionals *both* to support children with autism and other developmental disabilities and their families. As the focus of this study was primarily on the stresses and coping strategies of parent of children with autism and other developmental disabilities, we are particularly concerned about the lack of mental health services and trained providers of mental health services in China (Shi et al. 2005; Xiao et al. 2006). Those who provide family therapy services in China are typically psychiatrists, neurologists, and general practitioners. In fact, most mental health practitioners in China are physicians (Qian et al. 2002).

Qian et al. (2002) suggest that both the "cultural environment" and the "social attitudes of the Chinese" influence the way that families and others perceive "help-seeking behavior" (p. 51); and those who "do seek services tend to do so at facilities that are distant from their homes" (p. 52). Traditionally, family issues remain within the family. In other words, families try to resolve everything on their own. Just recently, western style family therapy was introduced to China and is beginning to be accepted by Chinese, but there is still a significant shortage of trained family therapists (Li and Liang 2005; Shi et al. 2005).

This is not the case in western countries as federal and state governments designate family therapy as a core mental health profession, licensed to treat families and regulated by such agencies as the American Association of Marriage and Family Therapists. In western countries family therapy has been found to be effective in helping families deal more effectively with family stress (Pinsof and Wynne 1995). When considered in terms of working with the "whole family," family therapy has been found to produce positive results with families with children with autism (Blackledge and Hayes 2006; Waltz 2002). Appropriately trained family therapists might successfully address many of the stresses on families we identified here as well as the concerns related to parenting skills we addressed previously (Wang and Michaels 2009), but with some specific cultural considerations that tie into some of the epistemological foundations of Chinese approaches to

wellness [i.e., “the unity and interconnectedness of the individual, society, and nature” (Qian et al. 2002, p. 64)].

Family therapists could utilize Satir’s growth model of family therapy as an approach to improve relationship oriented coping. A primary method of the growth model is to help families move from a hierarchical model to a growth model. This may initially seem counterintuitive to a culture based upon hierarchical collectivism as the emphasis is on self-fulfillment, equality of relationships, a multiplicity of approaches to problems, and an equal respect for sameness and difference are core components of the growth model (Satir et al. 1991). However, the growth model can be applied in the context of caregivers increasing their appreciation for their role as caregiver. Cheung and Chan (2002) determined the Satir growth model has been effective with Chinese families specifically in regard to congruent communication. The primary element behind this type of communication parallels a component of Chinese culture, taking others and context into the consideration of the communication message.

Family therapist might benefit from taking a direct, treatment approach characterized as solution focused with the therapist adopting the role of authoritative expert (Ma 2000). This differs slightly from the Satir growth model, which would address the ‘whole family’, but is consistent with the strategic model of family therapy. Adapting the expert approach may closely mirror the role of physicians and general practitioners, which may be more familiar to Chinese families. The overall goal of the family therapist would be to empower families with new coping skills rather than focusing on the dysfunction of the family system. In fact, Li and Liang (2005) offered that family therapists in China not dwell on a family’s shame or secrets and be directive and authoritative in sessions. Blackledge and Hayes 2006, also discussed that practitioners conduct ACT, Acceptance and Commitment Therapy as training sessions and even rename the therapy as Acceptance and Commitment Training.

Liu (2001) suggests that shame and guilt are frequently associated with disability in Chinese culture and that the stigma towards disability in China has an impact on family interactions with the larger environment. Disclosure of disability within a family (i.e., a child) can result in “loss of face” and may negatively affect the perceived prestige of the entire family. Thus families may adopt strategies to hide the existence of a disability, which could be a source of additional stress, especially for mothers.

Contrary to findings from studies on parents of children with developmental disabilities in Hong Kong, parents of children with autism in the current study reported the utilization of more active coping strategies, including acceptance, active coping, positive reinterpretation and growth, and suppression of competing activities and planning. This

may reflect the fact that this sample in some ways may represent a self-selected group of resilient and dedicated parents. Participants in this study at the time of data collection were all receiving services either through public or private institutions, which may indicate either a greater perceived level of stress or goal-oriented coping strategies than other families whose children with developmental disabilities are not receiving services. In other words, the stresses and coping strategies reported here only reflect those families who were already receiving services from private and public venues.

Therefore, some caution should be used when interpreting these findings. In all likelihood, the findings reported here do not completely capture the complexities of the stresses for families or the full repertoire of coping strategies utilized by families of children with autism and other developmental disabilities in the People’s Republic of China. The stresses and coping strategies employed by families of children with disabilities who are not receiving services, like those in rural and underdeveloped regions of the People’s Republic of China, remains unknown. Future research should strive to include participants from such under-represented areas in order to achieve a broader understanding of the perceived stresses and coping mechanisms of Chinese families.

Mothers in this sample tended to perceive more parent and family related problems than fathers. This might be explained in part by the expectations placed on Chinese mothers to take on three different roles simultaneously—the caregiver, the teacher of their child, and the wage earner (Huang et al. 1998; McCabe 2008). Mothers in this sample typically were the ones who left their jobs so that they could devote more time to the care of their children with developmental disabilities—including accompanying them to therapy sessions and serving as aides to their children during these sessions. McCabe (2008), on the contrary, suggests that the lives of fathers of children with developmental disabilities remain largely stable and that fathers for the most part are able to avoid most tasks associated with care-giving. The data from the current study suggest that this might, however, be somewhat of a façade as fathers were more likely than mothers to use substances as a strategy for coping with having a child with autism and other developmental disabilities.

Consistent with research findings in western countries, Chinese parents of children with autism appeared to report more stress in comparison to parents of children with other developmental disabilities. Surprisingly, parents of children with autism in this sample also reported greater usage of more active coping strategies than families of children with other types of developmental disabilities. One potential explanation for the increased levels of active coping among parents of children with autism might be that

regular public schools in the People's Republic of China typically do not to serve students with autism with the exception of a limited number of publicly funded special schools for children with intellectual disabilities (McCabe 2008; Wang 2008). These public schools for children with intellectual disabilities that also accept children with autism are only available in large cities. Despite the call for free public education for all children up to grade nine (Compulsory Education Law of the People's Republic of China 1986), statistics from 2008 indicate that approximately 36% of all school age children with disabilities were not receiving educational services within the People's Republic of China (China Disabled Persons' Federation, Beijing University, & National Bureau of Statistics of China 2009). This exclusion of so many children with developmental disabilities may be due in part to limited resources and a lack of trained professionals, curriculum materials, and facilities (McCabe and Tian 2002; Stratford and Ng 2000).

In other words, it may be out of sheer necessity that parents of children with autism in China develop more active coping strategies than parents of students with other developmental disabilities, as they are currently forced to assume the majority of the responsibility for educating and supporting their children. In large cities throughout China, there is a growing number of private schools for children with autism, however, the tuition to these schools are beyond the reach of many families. For those who could afford the tuition, few could sustain the expenses for an extended period of time (e.g., more than several months). On the other hand, parents of children with intellectual disabilities, at least in large cities in the People's Republic of China, find that there are at least some public special schools designed to provide educational supports to children with these developmental disabilities.

Parent training programs may be one strategy for managing stress levels in Chinese families of children with developmental disabilities, especially autism. Potential topics that might be addressed in these training programs could include understanding the specifics of various disabilities, typical and atypical growth and development, strategies and techniques for teaching specific skills, managing challenging behaviors, and utilizing available funding and support mechanisms.

These training programs could also serve an important support function for families. Having opportunities to meet other families with children with autism and other developmental disabilities, if properly facilitated and supported, might promote sharing and networking and the developing of more outcome-oriented coping strategies. Unfortunately, in the People's Republic of China, the fear of being stigmatized for having a child with autism and other developmental disabilities can deter families from seeking

assistance and/or sharing their experiences with other families of children with disabilities (Liu 2001).

Training programs are consistent with Chinese social policy and the use of ACT would fit nicely within this framework. However policy attention to training family therapists who are aware of specific family therapy models would be of benefit as attention to cultural values and beliefs would not be adjusted to fit the various models, but the models could be applied within cultural context. Also, even though progress has been made in terms of applying family therapy to Chinese families, some concern is noted by Pau (2000) when discussing how family participation in training programs and family therapy. Pau determined that while participants were able to recall positive changes that were achieved in the programs, many families went back to a cultural regime with a specific set of rules often in conflict with those learned in therapy. Regardless, Sim and Hu 2009, provided some hope for the future in discussing the enthusiasm many Chinese practitioners have toward family therapy despite culture beliefs that are not always in concurrence with some beliefs of family therapy. Sim and Hu used the aphorism of Deng Xiaoping (1904–1997): “It does not matter if it is a black cat or a white cat; a good cat is one that can catch the mice” (p. 562).

Ideally these family training and support groups would (a) actively engage in advocacy work with other families to break down some of the barriers facing families of children with autism and other developmental disabilities in China, and (b) create safe venues for other families to network and share experiences with each other and seek common solutions. Future studies should establish effective strategies for facilitating and supporting family therapy and family support groups in the People's Republic of China so that families of children with developmental disabilities, especially autism, are empowered to advocate for more inclusive schools and communities for themselves and their children.

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