



Original article

Coping Strategies among Caregivers of Children with Autism Spectrum Disorders: A Cluster Analysis

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ABSTRACT

Introduction/Background: The variability in coping strategies among caregivers of children with ASD may contribute to broader health outcomes; however, it is unclear if specific coping strategies are related to overall strain in this population. Therefore, this study identified groups of caregivers based on coping mechanisms and investigated differences in strain among groups. **Materials & Methods:** This study utilized a secondary data analysis, and included survey responses of 273 caregivers of children with ASD. Measures consisted of the COPE Inventory, and the Caregiver Strain Questionnaire. Data analyses consisted of cluster analysis to group caregiver coping strategies, and Analysis of Variance to compare the caregiver coping groups on strain level. **Results:** There were four distinct groups of caregivers of children with ASD with different coping styles: Social-Supported/ Planning, Spontaneous/ Reactive, Self-Supporting/ Reappraisal, and Religious/ Expressive. Caregivers in the Social-Supported/ Planning group demonstrated significantly higher levels than the remaining three groups in the use of the following coping strategies: planning, use of instrumental social support, and use of emotional social support, relative to the other three groups. Caregivers in the Spontaneous/ Reactive group used less restraint and less suppression of competing activities relative to the other three groups. Caregivers in the Self-Supporting/ Reappraisal showed more acceptance, and positive reinterpretation and growth coping strategies. Caregivers in the Religious/ Expressive group demonstrated significantly higher levels of religious coping relative to the other three groups and utilized more venting of emotions strategies. Groups did not differ on strain level. **Conclusion:** This study showed that caregivers of children with ASD may utilize differential combinations of coping strategies. Future research should investigate differences between groups of caregivers based subjective strain.

KEYWORDS: Cluster analysis, coping strategies, caregivers, ASD.

INTRODUCTION

Caregivers of children with Autism Spectrum Disorder (ASD) must develop strengths to overcome daily caregiving challenges and to manage stressful situations. Caregivers celebrate their children's successes every day, but their lives may involve additional caring demands due to therapies, changes in routines, and other child and family related needs [1]. As a result, caregivers of children with ASD develop coping mechanisms to overcome the stress and challenges,

in order to successfully parent their child. Given the demands of caring for a child with ASD, there has been an increase in targeted intervention approaches to promote caregiver well-being [2]. However, research suggests that there is variability in the coping strategies used among caregivers [1,3]; capturing homogeneity among such variable groups may help elucidate targeted intervention approaches for caregivers of children with ASD. Therefore, drawing from a large sample of caregivers of children with ASD, we identified groups of caregivers based on coping

strategies as well as investigated differences in strain among these groups.

Caregivers of children with ASD report higher levels of stress than caregivers of typical children [4] or those with other developmental conditions [5]. Particular characteristics of children with ASD, including autism severity [1,4,5], challenges in social interactions and communication [6], and challenging behaviors [5,6,7] can create stress throughout the household and the family. However, many caregivers adapt successfully to the demands of raising a child with ASD through the development of different coping mechanisms.

An early study on stress and coping [8] identified how people are similar or different in coping with the stressful events of daily living. By analyzing the ways that individuals cope with the stressful events of daily living over the course of one year, Folkman and Lazarus [8] found two types of highly used coping strategies: 1. *Problem-focused coping*, which is aimed at problem solving or doing something to alter the source of the stress; and 2. *Emotion-focused coping*, which is aimed at reducing or managing the emotional distress that is associated with the situation. Carver, Scheier, & Weintraub [9] investigated distinct activities within problem-focused and emotion-focused coping to separately measure the two coping strategies. In this study, researchers developed an instrument to assess people's coping styles and to distinguish between different coping strategies. The COPE Inventory [8] included five scales that measured conceptually distinct aspects of problem-focused coping (*Active coping, Planning, Suppression of competing activities, Restraint coping, Seeking of instrumental social support*), and five scales that measured distinct aspects of emotion-focused coping (*Seeking of emotional social support, Positive reinterpretation, Acceptance, Denial, Turning to religion*).

Several studies on caregiver coping highlighted a number of strategies as effective ways to overcome stress and improve health outcomes. For example, Zablotsky et al. [1] found that mothers of children with disabilities who utilized effective coping mechanisms were at a reduced risk for stress and mental health problems as compared to mothers with limited coping. Researchers also identified the strong social supports in the neighborhood as an important factor in protecting mothers' mental health. Similarly, Tway, Connolly and Novak [10] found that caregivers of children with ASD used social support systems within the family's social network as effective coping strategies. In this study, caregivers of children with ASD identified stress as significant and chronic in which seeking social support is very essential. Besides social coping, positive coping is another coping strategy that evidence identified as effective. Studies showed that positive reframing of potentially stressful events is an effective coping strategy under conditions where it is difficult to act directly to reduce the impact of the stressor [11,12]. Hastings et al. [11] found that positive coping was associated with lower levels of depression in mothers and fathers of children with ASD.

While some studies highlighted many coping strategies as effective, other studies identified some coping strategies as not helpful. For example, Phelps et al. [3] found that many caregivers used passive appraisals as an ineffective coping strategy for managing their child's ASD symptoms. In this

study, caregivers reported the use of passive behaviors because they believed they did not have the ability to alter the outcomes of their children. Additionally, evidence has shown mixed effects of religious coping in caregiver of children with ASD. While

Tarakeshwar and Pargament [13] found that religious coping may reduce stress and depression in parents of children with ASD, results in Hastings et al. [11] did not support this finding. Hastings et al. [11] found that active avoidance coping for caregivers of children with ASD was associated with more stress, anxiety and depression.

Given the differences in coping among caregivers, it is important to understand if specific ways that caregivers manage stress are related to overall strain. In the caregiver coping literature, caregiver strain refers to the demands, responsibilities, difficulties, and negative psychological consequences of caring for relatives with special needs [14,15]. Evidence shows that caregiver strain is a predictor of several negative outcomes on caregivers' health and wellbeing [16,17]. Previous studies of caregivers of children with ASD suggest that the use of passive avoidant coping strategies predict greater strain [18,19] and the lack of problem-focused coping is also associated with greater strain [18]. Research suggests three types of strain among caregiver: *Objective caregiver strain* (e.g., disrupted family relationships, interrupted routines, curtailed social activities, and loss of personal time); *Subjective externalized caregiver strain* (e.g., anger, resentment, embarrassment), and *Subjective internalized caregiver strain* (e.g., worry, guilt, sadness) [15]. Studies have found high levels of both subjective and objective strain among caregivers of children with ASD [20,21]. While different ways of coping may relate to subjective strain and subsequent depression among caregivers [4], it is unclear if coping styles are also associated with objective strain. If subjective strain helps understand caregivers' mental health, objective strain uncovers caregivers' daily life challenges (i.e., disrupted family relationships, interrupted routines). By knowing situations or challenges that most caregivers of children with ASD encounter every day, interventions will help target these challenges. Therefore, our exploratory cluster analysis on the COPE [9] expands upon existing studies of coping in caregivers of children with ASD.

This study aimed to identify groups of caregivers of children with ASD based on coping mechanisms, and to examine whether there are differences among these groups in terms of strain level.

MATERIALS AND METHODS

Research Design

The current study used secondary data analysis to identify groups (clusters) of caregivers of children with ASD based on their coping strategies. The larger study aimed to investigate the relationship between social support and health of caregivers of children with ASD as a tool for coping with stress. This study used secondary data from the larger study to further examine caregivers' coping and strain.

Participants

The original dataset consisted of 392 survey responses. Researchers included respondents if they reported that they had a child with an ASD and could read English. Researchers excluded caregivers of children with ASD if they reported that they were not the child's primary caregiver (e.g., teacher, therapist) or did not live in the same household as the child. Participants were recruited through a local hospital healthcare database, and through posting a survey link on social media platforms such as Facebook. After handling missing data, the current study included 273 survey responses. Characteristics of the sample are presented in Table 1.

Materials

The COPE Inventory [9]. The COPE was designed to assess a variety of coping strategies. Scales' scores from a total of sixty items are generated by summing across items for each subscale. Higher scores on the scales indicate a respondent's tendency to engage in a particular strategy [22]. Carver et al. [9] reported adequate internal consistency for the COPE for each of the subscales, with Cronbach's α reliabilities ranging from .45 to .92. We used items on each of the following categories on the COPE with the highest loadings: *Planning, Suppression of competing activities, Restraint, Use of instrumental social support, Use of emotional social support, Positive reinterpretation of growth, Acceptance, Religious coping, Focus on and venting of emotions, Denial, and Substance use* [9]. The original survey excluded the following COPE categories: Active coping, Behavioral disengagement, Mental disengagement, and Humor because these categories have poor item loadings [9].

The Caregiver Strain Questionnaire CGSQ [15]. The CGSQ contains 21 items rated on a five-point scale ranging from one (not at all a problem) to five (very much a problem) to assess the degree to which caregivers experience difficulties, strains, and other negative effects as the result of caring for a child with emotional or behavioral problems. The total CGSQ and its subscales demonstrated good internal consistency with Cronbach alpha coefficient for the entire scale .93 [15]. Khanna et al. [21] tested and validated the psychometric properties of the CGSQ among caregivers of children with ASD. Khanna et al. [21] found that the three-factor strain structure (Objective, Subjective internalized, and Subjective externalized strain) of CGSQ fitted better for caregivers' of children with ASD. The current study used the objective strain subscale of the CGSQ [21]. Previous research suggests that caregivers of children with ASD identify high levels of objective strain as compared to caregivers of children with DD [20].

Demographic Information Form: The original survey included information about the following caregiver and child characteristics: primary caregiver, child's age, child's sex, child's age when diagnosed, caregiver's relationship to child, caregiver's age, caregiver's sex, caregiver's level of education, and caregiver's marital status, and race/ethnicity.

Statistical Methods

We used SPSS version 22 to conduct analyses. To determine if there were groups (clusters) of caregivers of children with ASD with similar coping strategies, we performed cluster analysis using coping strategies as measured by the COPE Inventory. We used k-means cluster analysis with mean scores from each COPE subscale (Planning, Suppression of competing activities, Restraint, Use of instrumental social support, Use of emotional social support, Positive reinterpretation of growth, Acceptance, Religious coping, Focus on and venting of emotions, Denial, and Substance use) to create coping strategies categories.

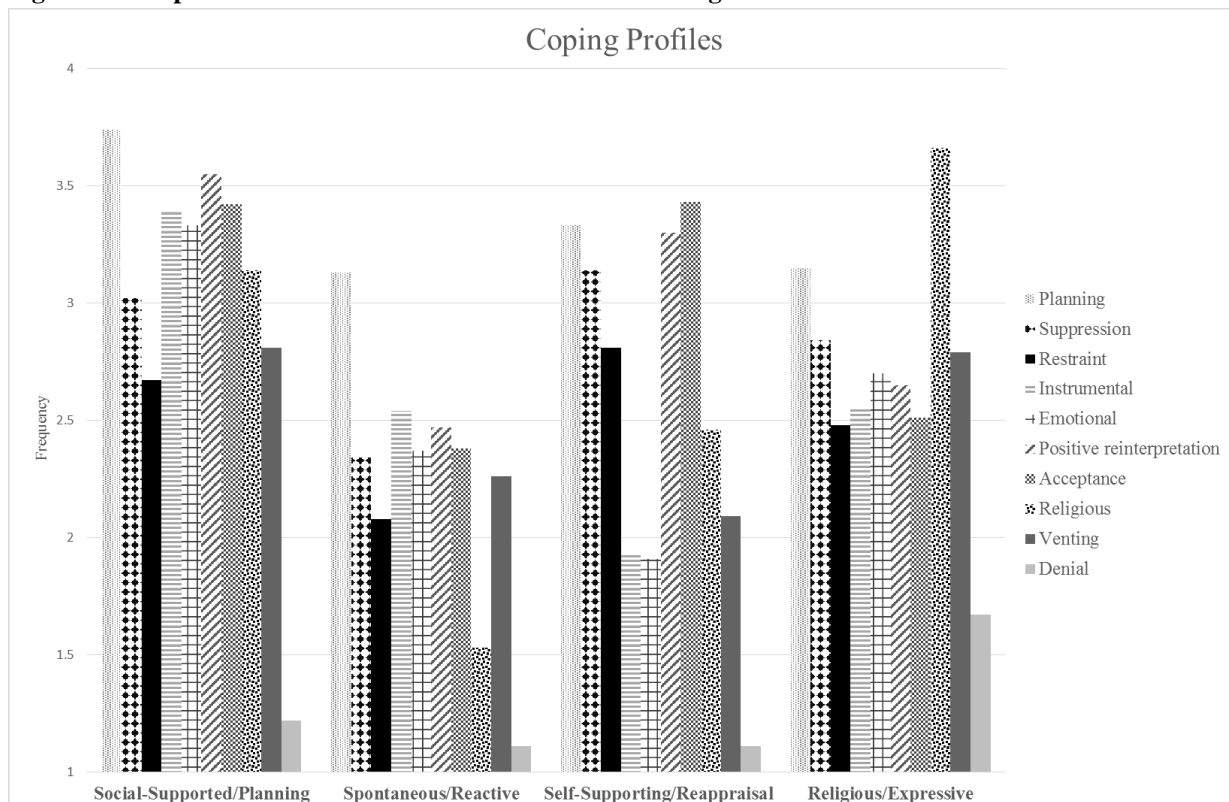
To determine the number of clusters that best fit our data, we compared the results from two, three, four and five-cluster solutions on the number of participants in each cluster, the differences between COPE items in different clusters, and on the potential interpretation of caregivers' coping characteristics between clusters. We used Bonferroni post hoc tests for multiple comparisons to evaluate differences between COPE items for cluster profile analysis (see Table 2), and to compare the four clusters on caregiver and child demographics. We first created a total objective strain subscale score for each caregiver. To determine if the clusters differed in objective strain, we performed Analysis of Variance (ANOVA) between the cluster membership and the objective strain subscale total score. We used Bonferroni post hoc tests to evaluate differences between the four caregiver clusters on the total objective strain subscale score.

RESULTS

We investigated results from two-five cluster analyses and ultimately selected the four-group cluster solution. The four-group cluster presented a reasonable distribution of participants across clusters (cluster n1= 89, n2= 79, n3= 54, n4= 51), comparisons between the four clusters showed significant differences, and the results demonstrated interpretable caregivers' characteristics between clusters (see Figure 1).

Cluster analysis results showed four distinct subgroups with different combinations of coping strategies: *Social-Supported/Planning (group one), Spontaneous/Reactive (group two), Self-Supporting/Reappraisal (group three), and Religious/Expressive (group four)*. Caregivers in group one (Social-Supported/Planning) demonstrated significantly higher levels than the remaining three groups in the use of the following coping strategies: *Planning, Use of instrumental social support, and Use of emotional social support*, relative to the other three groups (all $p < .05$) (see Table 2). In contrast, caregivers in group three (Self-Supporting/Reappraisal) demonstrated significantly lower levels of the *Use of instrumental social support and the Use of Emotional social support* relative to the other three groups (all $p < .05$). Additionally, caregivers in group three showed more in *Acceptance* (more than groups two and four, $p < .05$), and *Positive reinterpretation and growth* (more than groups two and four, $p < .05$) coping strategies.

Figure: 1 Comparison between Clusters on Mean COPE Categories



Caregivers in group four (Religious/Expressive) demonstrated significantly higher levels of *Religious coping* relative to the other three groups (all $p < .05$), and *Focus on and Venting of emotions* strategies (more than groups two and three, $p < .05$). Caregivers in group two (Spontaneous/Reactive) used less *Restraint* relative to the other three groups (all $p < .05$), and less *Suppression of competing activities* relative to the other three groups (all $p < .05$) as coping strategies. Also, group two showed significantly lower levels of *Religious coping* as compared to the other three groups (all $p < .05$).

ANOVA results showed no significant differences between the four groups on the objective subscale strain scores. The mean value for each cluster: Social-Supported/Planning (group one) = 2.98 (.97), Spontaneous/Reactive (group two) = 2.97 (1.08), Self-Supporting/Reappraisal (group three) = 2.99 (1.04), and Religious/Expressive (group four) = 2.99 (1.12). Previous findings among caregivers of children with ASD show that the mean objective strain ranges from 2.31 [23] to 2.71 [21].

Table 1 Demographic Characteristics of the Sample

Child and Caregiver Demographic Characteristics		Participants N= 273
Primary Caregiver	Yes	271 (99.6%)
	No	1 (0.4%)
	Missing	1 (0.4%)
Child Gender	Male	209 (76.6%)
	Female	59 (21.6%)
	Unknown	5 (1.8%)
Race	American Indian or Alaska Native	6 (2.2%)
	Asian	10 (3.7%)
	Black or African American	13 (4.8%)
	Hispanic or Latino	23 (8.4%)
	Native Hawaiian or Pacific Islander	2 (0.7%)
	White	238 (87.2%)
Caregiver Gender	Male	16 (5.9%)
	Female	249 (91.2%)
	Missing	8 (2.9%)
Caregiver Marital Status	Yes	225 (82.4%)

	No	46 (16.8%)
	Missing	2 (0.7%)
Caregiver Educational Level	Less than high school	5 (1.8%)
	High school	67 (24.5%)
	Associate degree	47 (17.2%)
	Bachelor degree	79 (28.9%)
	Master's degree	63 (23.1%)
	Doctoral degree	10 (3.7%)

Table 2 Differences between Caregivers' Groups on COPE Strategies

Coping Strategy	Social-Supported/Planning	Spontaneous/Reactive	Self-Supporting/Reappraisal	Religious/Expressive	F	p	Tukey's HSD
Planning	3.74	3.13	3.33	3.15	14.05	.000	1>2,3,4
Suppression of competing activities	3.02	2.34	3.14	2.84	22.41	.000	2<1,3,4
Restraint	2.67	2.08	2.81	2.48	13.16	.000	2<1,3,4
Instrumental use of social support	3.40	2.54	1.93	2.55	47.79	.000	1>2,3,4
Emotional use of social support	3.33	2.37	1.91	2.70	55.96	.000	1>2,3,4
Positive reinterpretation and growth	3.55	2.47	3.30	2.65	42.72	.000	3>2,4
Acceptance	3.42	2.38	3.43	2.51	39.93	.000	3>2,4
Religious coping	3.14	1.53	2.46	3.66	79.17	.000	4>1,2,3
Focus on and venting of emotions	2.81	2.26	2.09	2.79	19.38	.000	4>2,3
Denial	1.22	1.11	1.11	1.67	15.02	.000	4>1,2,3
Substance use	1.20	1.43	1.20	1.37	2.81	.04	

DISCUSSION

This study identified groups of caregivers of children with ASD that have distinct coping styles and compared these groups of caregivers on their sense of objective strain. Our findings showed that there were four distinct groups of caregivers of children with ASD with different coping styles: Social-Supported/Planning, Spontaneous/Reactive, Self-Supporting/Reappraisal, and Religious/Expressive coping styles.

Each caregiver group engaged in a combination of coping strategies to overcome the strain of caregiving. Although we hypothesized that the four caregivers' groups would differ on their sense of objective strain, our findings showed no significant differences. It may be surprising that the groups with different combinations of coping strategies did not differ on objective strain as previous studies suggest that

engagement in certain coping strategies (i.e., social supports) reduces stress [10] in comparisons to other coping strategies (i.e., passive re-appraisal) [3].

Caregivers with a Social-Supported/Planning coping style utilized Planning, Use of instrumental social support, and Use of emotional social support as strategies to a greater extent than the other three groups. Caregivers in this group also used Positive reinterpretation and growth as well as Acceptance coping strategies more frequently. It is possible that the social support received by caregivers in this group allowed for guidance and assistance in planning daily life. Or perhaps caregivers of children with ASD may benefit from extra time to plan therapy or family activities while other family members or friends care for their children with ASD.

Social support is essential as caring for a child with an ASD can present intense and stressful challenges that tend to stretch the resources of the caregiver [19]. In fact, evidence shows that higher utilization of social support is associated with significant decrease in individual and family stress [4,19]. Perhaps the high utilization of social supports by caregivers in this group helped them to manage their stressors.

In contrast, caregivers with a Spontaneous/Reactive coping style engaged less frequently in the Use of instrumental social support and the Use of emotional social support as coping strategies. Further, caregivers in this group minimally utilized Suppression of competing activities and Restraint as coping strategies. Caregivers in this group may have limited social systems of families and friends preventing their use of social coping strategies.

Just as group one's strong social network may make it possible for them to plan, it could be that group two's limited social network makes it challenging to engage in a planning coping strategy. Suppression of competing activities and using Restraint coping strategies requires planning, so it is likely the low use of all three of these strategies is a fundamental feature of this group. While we only investigated the effect of coping style group on objective strain, caregivers in the Spontaneous/Reactive group may show differences on subjective strain if they are lacking social support, particularly with interpersonal relationships.

Caregivers in group two have developed skills to quickly respond to daily situations, with management skills to respond to situations without previous planning. Though caregivers in this study appear to have effective coping strategies to manage strain, literature suggests the long-term use of passive avoidant coping strategies increase stress, and mental and physical health [19]. The Spontaneous/Reactive strategies utilized by group two may be considered passive and could have longer term implications, particularly for caregivers with younger children or a new diagnosis of ASD.

Caregivers of children with ASD in group three (Self-Supporting/Reappraisal) used less instrumental and emotional social coping strategies. While caregivers in this group limited their Use of instrumental social support and their Use of emotional social support, they focused on Positive reinterpretation and growth and Acceptance as coping strategies. Research shows that higher levels of problem-focused coping and lower levels of emotion-focused coping were associated with better caregiver wellbeing [11,24].

Similar to group one (Social-Supported/Planning), caregivers in group three used a high level of planning coping strategy. The limited interaction with families and friends may have allowed caregivers in group three to have more time to reinterpret situations and learn from different experiences. This group may not use socialization opportunities to discuss coping with their child's condition. Also, caregivers in this group may not seek others' help as they become more familial with their children's condition. Perhaps caregivers in this group may fear negative responses from others as they seek social support [25].

Another coping style that emerged in this study was the Religious/Expressive coping style of group four. Caregivers in this group utilized Religious coping much more than the remaining three groups, and combined this strategy with Venting of emotions and Suppression of competing activities as coping strategies. Although the use of Denial as a coping strategy was relatively low among all groups, caregivers with Religious/Expressive coping style adopt Denial at a significantly higher rate than other groups. It might be that this group's strong religious beliefs as a powerful coping strategy led them to be hopeful of improvement of their child's condition. Research suggests that religious coping may not result in better long-term outcomes for individuals with ASD [4] when compared to task-oriented, or distraction coping [26], though caregivers in this group did not differ in caregiver strain from other groups in our analysis.

Caregivers in the current sample showed slightly higher levels of objective strain than previously reported [20,21,23]. The combinations of coping strategies did not differentially influence objective strain in the current sample. It may be that different coping styles are more associated with subjective strain as research suggests that caregiver depression and anxiety, subjective strain, and coping are related [23]. Overall, findings point to the need for caregivers of children with ASD to engage in interventions that decrease objective strain. Family programs that are grounded in ways to directly impact objective strain such as making caregivers aware of respite opportunities; managing difficult and busy family routines, and promoting social outings are needed. Such interventions may not be dependent on ways of caregiving coping per se, but would likely impact the immense objective strain experienced by all families in the current study.

CONCLUSION

There are four distinct groups with different combinations of coping strategies: Social-Supported/Planning, Spontaneous/Reactive, Self-Supporting/Reappraisal, and Religious/Expressive. Each caregiver group engaged in a combination of coping strategies to overcome the strain of caregiving.

Limitations and Future Directions

While this study had a large sample size, the sample had limited diversity. Most caregivers reported their race/ethnicity as white, and that they were married. Another limitation is using sections of the assessment tools, rather than the entire measures. We included only the objective strain domain of the CGSQ as caregivers of children with ASD, and future research should investigate differences between subtypes of caregivers based on coping and subjective strain. While cluster analysis can reveal unique coping styles, it does not illustrate if caregivers have unique personal skills or contextual supports influencing their coping.

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