IIT Lewis College of Human Sciences
ILLINOIS INSTITUTE OF TECHNOLOGY

Coping Strategies in Family Caregivers of Transition Age Youth with Neurodevelopmental Disabilities

Melissa Ivins-Lukse[1], Dylan Saks[1], Samantha DeDios-Stern[1], Eun-Jeong Lee[1], Jinhee Park[2], Jing Chun[2], Heechan Park[3]
[1]Illinois Institute of Technology, [2]Michigan State University, [3]The Catholic University of Korea

Introduction

Caring for a child during the transition to adulthood is challenging for any caregiver, but this difficult time can be even more stressful for parents of youth with neurodevelopmental disorders. Parents play an essential role in providing care and support as their children transition to adulthood (Boehm et al., 2015; Smith et al., 2012), with many expectations, changes (both anticipated and unanticipated), as well as recurring and new challenges for both children and parents. Though coping strategies have been associated with parental stress and well-being (Hastings et al., 2005), the use of coping strategies among family caregivers of transition-age youth with neurodevelopmental disorders has not been studied. This study seeks to explore the coping strategies used by family caregivers (primarily mothers) of transition-age youth with neurodevelopmental disorders through principle component analysis to uncover the structure of coping strategies used. This study also seeks to identify associations between coping dimensions and caregiver perceived stress, resilience, and depression.

Methods

Participants

- 172 family caregivers in South Korea providing care for youth with neurodevelopmental disabilities
  - Caregiver gender: 82% female
  - Relationship to youth: 82% mothers, 12% fathers, 6% other relatives
  - Participant age: *M* = 47.61; *SD* = 6.11
  - Youth's diagnosis: 51% Intellectual Disability, 25% Developmental Disability, 24% Autism Spectrum Disorder
  - Youth age: *M* = 18.48; *SD* = 1.48
- Participants were recruited by teachers at the youths' schools and completed hard copies of all surveys

Measures

- ***Brief COPE:*** 28-item self-report questionnaire measuring how frequently different coping strategies are used.
- ***Perceived Stress Scale (PSS):*** 14-item self-report inventory that gauges the level of stress one perceives in his or her life.
- ***10-item Connor-Davidson Resilience Scale (CD-RISC):*** self-report scale assessing one's level of resilience.
- ***Center for Epidemiologic Studies Depression Scale (CES-D):*** 10-item self-report scale measuring common symptoms of depression.

Data Analysis

- **Principle component analysis** (PCA) with oblique rotation (direct oblimin) was conducted using SPSS version 23 (IBM Corp., 2015).
- **Parallel analysis** was conducted using the Parallel Analysis Engine (Patil, Singh, Mishra, & Donovan, 2007) to determine the number of components to extract. 100 random correlation matrices were generated and the mean 95th percentile for each component eigenvalue was used for comparison.

Results

- Four components were extracted, explaining 49% of the variance in total:
  - 1) Active Acceptance (9 items, 22% variance)
  - 2) Dysfunctional (9 items, 14% variance)
  - 3) Engagement (5 items, 7% variance)
  - 4) Substance Use (2 items, 6% variance)

Table 1. PCA of Caregivers' Coping Strategies

	Component Loadings			
I've been... [Coping strategy in brackets]	Active Accept.	Dys-funct.	Engag-ement	Sub. Use
✚...looking for something good in what is happening. [Positive Reframing]	**.754**	-.011	-.076	-.053
■...trying to come up with a strategy about what to do. [Planning]	**.732**	.014	.145	.077
■...thinking hard about what steps to take. [Planning]	**.732**	-.086	-.002	.117
✚...getting comfort and understanding from someone. [Using Emotional Support]	**.666**	.100	-.122	-.111
✚...learning to live with it. [Acceptance]	**.663**	-.072	-.216	.096
✚...trying to see it in a different light, to make it seem more positive. [Positive Reframing]	**.652**	-.112	-.025	-.119
■...taking action to try to make the situation better. [Active Coping]	**.606**	-.083	-.218	.272
✚...accepting the reality of the fact that it has happened. [Acceptance]	**.548**	-.081	.078	-.046
■...getting help and advice from other people. [Using Instrumental Support]	**.545**	.071	-.236	-.074
O...been refusing to believe that it has happened. [Denial]	-.261	**.757**	-.067	.057
O...giving up trying to deal with it. [Behavioral Disengagement]	-.025	**.645**	.109	.051
O...criticizing myself. [Self-Blame]	-.142	**.637**	.115	.167
O...blaming myself for things that happened. [Self-Blame}	.016	**.587**	.091	.157
O...saying things to let my unpleasant feelings escape. [Venting]	-.017	**.579**	-.089	-.060
✚...making jokes about it. {Humor}	*.457*	*.526*	*.109*	*-.082*
O...giving up the attempt to cope. [Behavioral Disengagement]	-.211	**.523**	-.015	.189
O...expressing my negative feelings. [Venting]	.291	**.518**	.033	.062
O...saying to myself "this isn't real". [Denial]	-.270	**.468**	-.320	-.073
O...doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping. [Self-Distraction]	.083	**.465**	-.175	-.319
✚...praying or meditating. [Religion]	-.014	-.004	**-.820**	-.045
✚...trying to find comfort in my religion or spiritual beliefs. [Religion}	-.141	-.098	**-.792**	-.075
O...turning to work or other activities to take my mind off things. [Self-Distraction]	.079	.007	**-.614**	.180
■...concentrating my efforts on doing something about the situation I'm in. [Active Coping]	.242	-.143	**-.605**	.200
■...trying to get advice or help from other people about what to do. [Using Instrumental Support]	.382	.064	**-.471**	-.073
✚...getting emotional support from others. [Using Emotional Support]	*.362*	*.118*	*-.378*	*-.061*
✚...making fun of the situation. {Humor}	*.142*	*.254*	*-.290*	*-.173*
O...using alcohol or other drugs to make myself feel better. [Substance Use]	.059	.132	-.062	**.866**
O...using alcohol or other drugs to help me get through it. [Substance Use]	.012	.270	-.097	**.820**

Note: Items in italics and grey font were not counted as loading on a component due to either multiple (two or more >.40) or insufficient (all <.40) loadings. For comparison, categorization of coping strategies by Cooper, Katona, and Livingston (2008) designated as ✚ = emotion-focused, ■ = problem-focused, and O = dysfunctional coping.

Table 2. Correlations between Caregiver Coping Components and Caregiver Wellbeing

	1.	2.	3.	4.	CES-D	CD-RISC	PSS
1. Active Acceptance	--	-.092	.470***	.002	.044	.542***	-.395***
2. Dysfunctional	--	--	.111	.285***	.279***	-.240**	.337***
3. Engagement	--	--	--	-.017	-.012	.357***	-.163*
4. Substance Use	--	--	--	--	.123	-.029	.085

*Note: *p<.05, **p<.01, ***p<.001*

Major Findings

Comparison of eigenvalues with parallel analysis led to extraction of four components: 1) Active Acceptance (9 items), 2) Dysfunctional (9 items), 3) Engagement (5 items), and 4) Substance Use (2 items), which explained 22%, 14%, 7%, and 6% of the variance, respectively, and 49% in total. Three items were omitted due to multiple and/or insufficient loadings.

Active Acceptance was significantly associated with lower perceived stress (r = -.40, p < .001) and higher resilience (r = .54, p < .001), but not with depressive symptoms. Engagement exhibited the same pattern, a negative correlation with perceived stress (r = -.16, p < .05) and a positive correlation with resilience (r = .36, p < .001). Unsurprisingly, these two coping components shared a positive association with each other (r = .47, p < .001).

In contrast, the Dysfunctional component was associated with more depressive symptoms (r = .28, p < .001), higher perceived stress (r = .34, p < .001), and lower resilience (r = -.24, p < .01). The Substance Use component was not significantly associated with any wellbeing measures (p > .05), but was positively associated with the Dysfunctional coping component (r= .29, p < .001).

Cooper, Katona, and Livingston (2008) previously grouped the strategies included in the Brief COPE into three theoretically based groups: emotion-focused, problem-focused, and dysfunctional coping. With the exception of one self-distraction item and the two substance use items, all items that Cooper and colleagues classified as dysfunctional coping loaded onto one component (also termed "Dysfunctional"). Interestingly, the items classified as emotion- or problem-focused coping were evenly represented among the two more adaptive components (Active Acceptance, Engagement), possibly indicating that caregivers tend to use a mix of these coping strategies, rather than favoring one exclusively over the other.

Limitations & Implications

This study uncovered four components of coping among the strategies employed by family caregivers of transition-age youth with neurodevelopmental disorders. Understanding how these coping components are associated with caregivers' perceived stress, resilience, and depressive symptoms could assist clinicians in promoting positive psychosocial adaptation for these family members. Notably, only the dysfunctional component was associated with depressive symptoms. Thus for caregivers who primarily use these more negative and avoidant strategies, it will be critical for rehabilitation professionals to provide coaching in using more adaptive coping strategies (e.g., Active Acceptance, Engagement) that are associated with higher resilience and lower perceived stress. Limitations of this study include the limited item pool and the cross-sectional study design.