

Caring for Youth with Co-occurring Developmental Disabilities and Behavioral Health Issues when Caregivers Face Additional Health-Related Stressors

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Background

Approximately 15% of children and adolescents in the U.S. experience a developmental disability (DD) and approximately 30% of these youth also have a diagnosable mental or behavioral health issue (Boyle et al., 2011; National Association for Persons with Developmental Disabilities and Mental Health Needs, 2016). Studies show that caregivers of youth with co-occurring DD and behavioral health issues experience the highest levels of caregiving strain (Martorell, Gutierrez-Recacha, Irazabal, Marsa, & Garcia, 2011). In addition, many of these caregivers must also deal with their own or another family member's chronic health condition, stressors which may place them at even greater risk for poor outcomes (Gallagher & Hannigan, 2015; Grinstead, Leder, Jensen, & Bond, 2003; Pinquart & Sorensen, 2007).

The aims of this study are to: (1) Provide a descriptive "snapshot" of caregivers of youth with co-occurring DD and behavioral health issues; (2) identify similarities and differences in risk and protective factors among three groups of caregivers with graduated levels of health-related stressors (i.e., those focused on providing care for the target youth with DD; without additional health-related stressors with which to contend; those contending with minor health-related stressors; and, those contending with major health-related stressors), and; (3) examine the relative contribution of risk and protective factors to objective, subjective internalized, and subjective externalized caregiving strain in this DD caregiver population.

Methods

Design and procedures. We conducted a secondary analysis of baseline (at program enrollment) and 6-month follow-up data from family caregivers participating in SAMHSA's Longitudinal Child and Family Outcome Study (see Manteuffel, Stephens, Brashears, Krivelyova, & Fisher, 2008). Determination of youth DD status was based on caregiver report of youth "having an Individualized Education Plan" ($N = 3,819$) for the primary reason of "developmental disability" ($n = 600$). Caregivers were stratified into groups based on self-reported "recurring or chronic physical health problems" for themselves or another household member and the degree to which these problems affected their ability to provide care for the youth with DD. The final sample consisted of family caregivers without additional health-related stressors ($n = 202$), with minor additional health-related stressors ($n = 304$), and with major additional health-related stressors ($n = 94$).

Measures. 1) *Revised Caregiver Information Questionnaire* (CMHS, 2005), 2) *Family Life Questionnaire* (CMHS, 2005), 3) *Child Behavior Checklist/6-18* (Achenbach & Rescorla, 2001), 4) *Caregiver Strain Questionnaire* (Brannan, Heflinger, & Bickman, 1997), 5) *Youth Services Survey for Families and Multi-Sector Services Contacts Questionnaire* (CMHS, 2005) and 6) *Revised Youth Information Questionnaire* (CMHS, 2005).

Analysis. Analyses were conducted using SPSS version 22 (IBM Corp., 2013). One-way Analysis of Variance (ANOVA) tests (i.e., for continuous variables) and chi-square tests (i.e., for categorical variables) were used to explore caregiver group differences in risk and protective factors at program enrollment. Hierarchical linear regression with 6-month follow-up caregiving strain subscale scores as the dependent variables was used to identify predictors of objective, subjective internalized, and subjective externalized caregiving strain. The sample for the regression analyses included caregivers for whom 6-month follow-up data on the strain outcomes were available.

Results

Table 1. Overall, caregivers were predominantly female (92%), white (66%), relatively well-educated (81.2% with at least a high school diploma), and living at or below the poverty level (71%).

Table 1.

Characteristics of the study sample (N=600)	
Caregiver age in years, Mean (SD)	39.15 (9.67)
Caregiver sex (female), n (%)	549 (91.5)
Caregiver employment (unemployed), n (%)	312 (52.1)
Caregiver race	
White only, n (%)	331 (56.0)
Asian only, n (%)	5 (.8)
Black or African American only, n (%)	129 (21.8)
American Indian or Alaskan Native only, n (%)	13 (2.2)
Hispanic, n (%)	72 (12.2)
Native Hawaiian or Pacific Islander only, n (%)	5 (.8)
Multiracial, n (%)	36 (6.1)
Caregiver education	
Less than high school, n (%)	113 (18.8)
High school diploma or GED, n (%)	215 (35.8)
Associate degree, n (%)	48 (8.0)
Some college, no degree, n (%)	150 (25.0)
Bachelor's degree or higher, n (%)	74 (12.3)
Caregiver relationship to youth	
Biological parent, n (%)	452 (76.2)
Adoptive/stepparent, n (%)	52 (8.8)
Foster parent, n (%)	23 (3.9)
Aunt or uncle, n (%)	11 (1.9)
Grandparent, n (%)	46 (7.8)
Other, n (%)	9 (1.5)
Annual household income (at or below poverty), n (%)	405 (70.6)
Total children in household (Mean, SD)	2.53 (1.59)
Total adults in household (Mean, SD)	1.88 (.94)

Note. SD = standard deviation

Table 3

Comparison of protective factors by DD caregiver group (N=600)		DD caregivers w/out AHRS (n _i =202)		DD caregivers with minor AHRS (n _i =304)		DD caregivers with major AHRS (n _i =94)		F, χ^2	p
<i>Individual caregiver factors</i>									
Behavioral health literacy/empowerment (Mean, SD)	21.39	3.19	21.44	3.11	20.49	3.70	2.34	.097	
<i>Interpersonal and family factors</i>									
Relationship to youth (biological), n (%)	175	87.1	255	84.2	85	90.4	2.58	.275	
Other supportive adult, n (%)	158	79.8	256	85.0	79	84.0	2.42	.299	
Time for family (half of the time or more), n (%)	173	86.1	268	88.4	76	80.9	3.58	.167	
Time for self or friends (half of the time+), n (%)	31	15.4	28	9.2	7	7.4	6.17	.046	
Family quality of life (Mean, SD)	34.64	6.52	34.88	6.88	32.99	6.77	2.85	.058	
<i>Formal support services received</i>									
Case management, n (%)	94	67.6	161	72.2	57	77.0	2.19	.335	
Family therapy, n (%)	34	24.3	73	32.9	25	33.8	3.56	.172	
Day treatment, n (%)	8	5.7	15	6.7	9	12.0	3.08	.215	
Family support, n (%)	35	25.0	61	27.4	21	28.0	.320	.852	
Transportation, n (%)	38	27.1	58	26.0	14	18.7	2.06	.357	
Respite, n (%)	25	17.9	36	16.3	9	12.2	1.18	.555	
<i>Community and cultural factors</i>									
Location and availability of services (Mean, SD)	8.43	1.78	8.29	1.72	7.91	2.29	1.84	.160	
Cultural sensitivity of providers (Mean, SD)	17.93	2.13	17.57	2.58	17.51	2.62	1.01	.367	

Note. AHRS = additional health-related stressors. SD = standard deviation. P-values for differences between caregiver groups based on chi-square test for categorical variables and one-way Analysis of Variance tests for continuous variables. All variables measured at program enrollment, except for support services received (n_i=140, n_i=223, n_i=75) and service location and cultural sensitivity variables (n_i=135, n_i=221, n_i=72) which were measured at six months.

Table 4.

Results of Hierarchical Regressions Predicting Objective, Internalized, and Externalized Caregiving Strain at Six Months (N=444)

	Objective Strain					Subjective Internalized Strain					Subjective Externalized Strain				
	B	95%CI	p	R ²	ΔF	B	95%CI	p	R ²	ΔF	B	95%CI	p	R ²	ΔF
<i>Block 1: Caregiver demographic factors</i>															
CG age in years	.036	-.009-.017	.534			-.027	-.016-.010	.646			.008	-.011-.013	.888		
CG sex (male)	.006	-.383-.430	.911		1.177	-.067	-.663-.162	.233			-.67	-.633-.156	.235		
CG employment (unemployed)	.088	-.047-.409	.119	.014		.060	-.109-.354	.297	.027	2.361	.073	-.080-.362	.211	.019	1.629
<i>Block 2: Risk factors</i>															
CG recent depression (yes)	.044	-.108-.351	.490			.078	-.104-.422	.336			.085	-.086-.418	.196		
CG recent other mental illness (yes)	-.025	-.353-.232	.684			-.040	-.391-.202	.532			.024	-.239-.339	.702		
CG w/out AHRS	reference					reference					reference				
CG with minor AHRS	-.135	-.539-.023	.033	.256***	13.547***	-.132	-.533-.009	.043	.210***	9.668***	-.082	-.411-.090	.109	.201***	9.486***
CG with major AHRS	-.073	-.570-.158	.265			-.049	-.504-.234	.473			-.050	-.484-.221	.463		
Youth internalizing behavior	.113	-.001-.023	.064			.198	.007-.032	.002			.006	-.011-.012	.926		
Youth externalizing behavior	.402	.025-.047	-.001			.335	.010-.032	-.001			.346	.019-.040	-.001		
<i>Block 3: Protective factors</i>															
CG behavioral health literacy/empowerment	.100	-.003-.066	.074			.030	-.026-.044	.605			.045	-.020-.046	.438		
CG time for self or friends (≥ half the time)	-.120	-.385-.084	.018	.295***	4.588**	-.144	-.931-.118	.012	.250***	4.341**	-.045	-.547-.231	.424	.250***	5.443**
CG family quality of life	-.113	-.635-.090	.052			-.132	-.639-.002	.027			-.128	-.699-.016	-.001		

Note. CG = caregiver. AHRS = additional health-related stressors. B represents standardized beta coefficients. p-values for F and F change, * $p < .05$; ** $p < .01$; *** $p < .001$.

Table 4. Hierarchical regression models predicting objective caregiving strain, subjective internalized caregiving strain, and subjective externalized caregiving strain at six months. Caregivers dealing with minor additional health-related stressors had significantly lower levels of objective strain and subjective internalized strain. Caregivers who reported higher levels of youth internalizing behavior experienced higher levels of subjective internalized strain and those reporting higher levels of youth externalizing behavior experienced higher levels of objective strain, subjective internalized strain, and subjective externalized strain. More time for self or family was associated with lower objective strain and subjective internalized strain, and higher family quality of life was associated with lower subjective internalized strain and subjective externalized strain.

Table 2.

Comparison of risk factors by DD caregiver group (N=600)		DD caregivers w/out AHRS (n _i =202)		DD caregivers with minor AHRS (n _i =304)		DD caregivers with major AHRS (n _i =94)		F, χ^2	p
<i>Individual caregiver factors</i>									
Age in years (Mean, SD)	38.08	9.29	39.47	9.96	40.37	9.41	2.13	.119	
Sex (male), n (%)	18	8.9	26	8.6	7	7.4	1.79	.914	
Race (white), n (%)	121	63.0	205	68.6	60	64.5	1.73	.422	
Education (< high school), n (%)	39	19.3	61	20.1	13	13.8	1.87	.392	
Current unemployment, n (%)	93	46.0	156	51.5	63	67.0	11.41	.003	
At or below poverty, n (%)	138	72.3	200	68.0	67	75.3	2.13	.345	
Recent problem with alcohol or drugs, n (%)	13	6.5	17	5.7	8	8.7	1.08	.583	
Recent problem with depression, n (%)	73	36.5	147	48.8	64	69.6	27.83	<.001	
Recent problem with other mental illness, n (%)	27	13.4	53	17.7	29	31.2	13.53	.001	
<i>Interpersonal and family factors</i>									
Total children in household (Mean, SD)	2.49	1.46	2.54	1.61	2.55	1.80	0.82	.921	
Youth internalizing behavior (Mean, SD)	19.34	10.47	18.65	9.42	25.12	9.96	12.66	<.001	
Youth externalizing behavior (Mean, SD)	27.86	12.16	28.50	12.19	32.99	14.54	4.93	.008	
Objective caregiving strain (Mean, SD)	31.73	11.19	31.17	11.40	37.28	10.02	11.09	<.001	
Internalized caregiving strain (Mean, SD)	21.85	5.87	21.33	5.83	24.28	4.51	9.79	<.001	
Externalized caregiving strain (Mean, SD)	8.86	3.73	8.74	3.79	9.96	3.92	3.75	.024	
Family history of alcohol or drug problems, n (%)	91	52.3	159	62.6	59	69.4	8.16	.017	
Family history of depression, n (%)	121	69.9	205	82.0	78	91.8	18.52	<.001	
Family history of other mental illness, n (%)	80	46.5	151	60.9	59	69.4	14.59	.001	
<i>Community and cultural factors</i>									
Non-violent neighborhood crime (yes), n (%)	21	28.8	25	21.2	11	26.2	1.49	.476	
Violent neighborhood crime (yes), n (%)	19	26.0	26	21.7	14	33.3	2.30	.317	

Note. AHRS = additional health-related stressors. SD = standard deviation. P-values for differences between caregiver groups based on chi-square test for categorical variables and one-way Analysis of Variance tests for continuous variables. All variables measured at program enrollment. Comparisons for family history factors restricted to biological caregivers only (n_i=174, n_i=254, n_i=85). Community and cultural factors by youth report (n_i=73, n_i=120, n_i=42).

A comparison of risk factors by caregiver group is presented in Table 2. Significant group differences were found on a variety of risk factors including current unemployment, recent problems with depression and other mental health issues, caregiver ratings of youth internalizing and externalizing behaviors, objective, subjective internalized, and subjective externalized caregiving strain, and family history of substance abuse problems, depression, and other mental illness.

Table 3. Protective factors between the three caregiver groups.

Lower proportion of caregivers with major additional health-related stressors reported having "time for self or friends" at least "half of the time". Marginally significant group differences were also found on the factors of behavioral health literacy and empowerment and family quality of life, with the major additional health-related stressors group reporting lower levels of each characteristic.

Discussion and Implications

This study is among the first to explore risk and protective factors in a national sample of caregivers of youth with co-occurring DD and behavioral health issues. There were several striking features in the overall sample (e.g., 71% were living in poverty compared with a 15% poverty rate in the U.S. adult population), as well as significant differences between groups (e.g., 70% of caregivers with major health stressors with recent depression compared with 37% in the group without health stressors). Although predictors of caregiving strain in this sample were similar to populations who do not experience DD, it is noteworthy that experiencing a minor health stressor appeared to be protective against strain. Findings showcase the need for healthcare providers and DD service providers to conduct brief health, mental health and service needs assessments to determine not only the child's but the whole family's information and referral needs so that the family receives appropriate services and supports.

This study illustrates the challenges that caregivers who deal with health issues and take care of youth who have co-occurring developmental disabilities and behavior health challenges face. Community-based service systems such as medical, mental health, and developmental disabilities services need to take a more holistic approach to serving youth who have co-occurring issues. In addition to providing services to the youth, they should also assess the family caregivers' needs and refer them to appropriate resources and services if warranted. Taking a more coordinated and comprehensive service approach will lead to better outcomes for patients/clients and their families. This is particularly important in light of the current and future changes to the DD services field in terms of the new Home and Community Based Services rule and in particular, the increased emphasis on community-based service delivery and living for people with disabilities.

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