Risk Factors Associated with Depressive Symptoms in Caregivers of Children with Type 1 Diabetes or Cystic Fibrosis

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Objective Evaluate depressive symptoms in caregivers of children with type 1 diabetes (T1D) or cystic fibrosis (CF) and identify associated risk factors. **Methods** A total of 195 caregivers completed demographic, stress, and depressive symptoms questionnaires. Children's health status was obtained from medical records. **Results** Approximately 33% of caregivers reported elevated symptoms of depression (i.e., exceeded clinical cutoff of 16 on the Center for Epidemiological Studies-Depression Scale). For caregivers of children with T1D, elevations were associated with less caregiver education, more family stress, older child age, and worse glycemic control. For caregivers of children with CF, more family stress and lack of employment outside of the home were associated with elevated depressive symptoms. **Conclusions** Many caregivers of children with T1D or CF experience depressive symptoms, although risk factors may differ in these two populations. Screening of caregiver depressive symptoms as part of routine clinic visits may provide opportunities for needed intervention.

Key words children; cystic fibrosis; depressive symptoms; health outcomes; parents; risk factors; type 1 diabetes.

Introduction

Recent estimates suggest that depression is a serious health problem with 10–25% of women and 7–12% of men experiencing at least one major depressive episode at some point in their lifetime (American Psychiatric Association, 2000; Kessler, Chiu, Demler, & Walters, 2005). Many studies have demonstrated that rates of depression are elevated in mothers of young children (Horwitz, Briggs-Gowan, Storfer-Isser, & Carter, 2007; McLearn, Minkovitz, Strobino, Marks, & Hou, 2006; McLennan, Kotelchuck, & Cho, 2001; Pascoe, Stolfi, & Ormond, 2006; Weissman & Jensen, 2002). Demographic risk factors associated with depression in mothers of children without chronic illness include low socioeconomic status, young maternal age, low education, single marital status, unemployment, stress, and nonwhite race/ethnicity (Heneghan, Silver, Bauman, Westbrook, & Stein, 1998; Horwitz et al., 2007; Kemper & Babonis, 1992; Lanzi, Pascoe, Keltner, & Ramey, 1999; McLennan et al., 2001; Orr, James, Burns, & Thompson, 1989; Pascoe et al., 2006). Mothers caring for children with chronic illnesses appear to be especially at-risk for the development of depressive symptoms (Kashikar-Zuck et al., 2008; McLennan et al., 2001; Sharghi, Karbakhsh, Nabaei, Meysamie, & Farrokhi, 2006; Yilmaz et al., 2008). However, to our knowledge, no studies have examined the impact of demographic or disease-related risk factors on the development of depressive symptoms in caregivers of children with type 1 diabetes (T1D) or cystic fibrosis (CF), which are two of the most demanding chronic illnesses to manage in children.

Both T1D and CF require parents to make significant lifestyle changes to accommodate their children's treatments. Both diseases require quarterly appointments with healthcare teams and their treatment regimens are time-consuming and complex. For example, meals and

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snacks need to be scheduled and caloric intake carefully monitored. Medications must be given and coordinated with food intake and disease status measured on a daily basis. In addition, unique lifestyle changes occur for each disease. Caregivers of children with T1D must coordinate treatment with school personnel and often become fearful of hypoglycemia (Patton, Dolan, Henry, & Powers, 2008; Streisand, Swift, Wickmark, Chen, & Holmes, 2005), whereas caregivers of children with CF encounter frequent hospitalizations due to pulmonary exacerbations and decreased amount of time spent in recreational activities (Modi, Marciel, Slater, Drotar, & Quittner, 2008; Quittner, Opipari, Regoli, Jacobsen, & Eigen, 1992).

Several studies of mothers caring for children with T1D or CF have documented elevated levels of depression (Horsch, McManus, Kennedy, & Edge, 2007; Jaser, Whittemore, Ambrosino, Lindemann, & Grey, 2008; Quittner, Espelage, Opipari, Carter, & Eigen, 1998). For example, 17–22% of female caregivers of children with T1D experienced elevated rates of depressive symptoms (Horsch et al., 2007; Jaser et al., 2008). In one of the only studies to assess depressive symptoms in both mothers and fathers of children with newly diagnosed T1D, Kovacs and colleagues (1985) found that 38% of female and 13% of male caregivers reported mild to moderate symptoms of depression. A similar pattern was found for caregivers of children with CF, with 28–44% of female caregivers reporting depressive symptoms compared to 12–33% of male caregivers (Glasscoe, Lancaster, Smyth, & Hill, 2007; Quittner et al., 1998).

Children's health status (i.e., how healthy a child is based on health outcome indicators for that particular disease) could potentially impact severity of caregiver depressive symptoms. Most studies have failed to evaluate the association between children's health outcomes (e.g., glycemic control in T1D; lung functioning or weight in CF) and caregiver depressive symptoms (Horsch et al., 2007; Kovacs et al., 1990). Although Jaser and colleagues (2008) did not find an association between caregiver depressive symptoms and glycemic control, the children in their study had well-controlled T1D. In contrast, poorer child lung functioning in patients with CF has been associated with increased depressive symptoms in their caregivers (Driscoll, Montag-Leifling, Acton, & Modi, 2009). Thus, one of the goals of the current study was to evaluate the association between children's health outcomes (i.e., glycemic control measured by hemoglobin A_1C in T1D and standardized body mass index—zBMI—in CF) and caregiver depressive symptoms.

There are several potential negative consequences for children of caregivers who experience depression including potential interference with a caregiver's ability to take responsibility for and adhere to treatment regimens (Naar-King et al., 2006; Quittner, Barker, Geller, Butt, & Gondor, 2007). In addition, children of depressed caregivers are at increased risk for developing depression as compared to children of nondepressed caregivers (Beardslee et al., 1996; Beardslee, Versage, & Gladstone, 1998). Moreover, children of depressed caregivers continue to experience difficulty in adulthood with higher rates of anxiety, substance abuse, and general psychosocial impairment (Weissman, Warner, Wickramaratne, Moreau, & Olfson, 1997; Weissman et al., 2006).

Taken together, it is important to identify risk factors associated with caregiver depressive symptoms so that preventive and intervention efforts can be made when appropriate. Therefore, the goals of the current study were to (a) describe the occurrence of depressive symptoms in female and male primary caregivers of children from two populations (i.e., T1D or CF), (b) evaluate the association between glycemic control in T1D and zBMI in CF and caregiver depressive symptoms, and (c) determine whether risk factors (e.g., demographics, stress) associated with depressive symptoms are similar for caregivers of children with T1D and caregivers of children with CF.

Methods

Participants

This study was part of the HANDling Diabetes/CF multisite, randomized clinical trial. The translational trial was designed to test the effectiveness of an adherence intervention delivered as part of the routine clinical care for young patients diagnosed with either T1D or CF. Because the intervention was designed as routine care, all families were invited to participate provided that the child was diagnosed at least 6 months prior and was less than 12 years of age. One hundred and ninety-five primary caregivers (108 caregivers of children with T1D and 87 caregivers of children with CF) participated in this study.

Pre-treatment Primary Caregiver Assessment

At the study's inception, primary caregivers completed a number of pre-treatment questionnaires.

Demographic Information

Each primary caregiver provided information about the child's sex, race/ethnicity, age, and health insurance; the child's parents' age, education, marital status, and employment status; and the age, sex and relationship to the child of all persons living in the household.

Depressive Symptoms

Primary caregiver depressive symptoms were measured using the 20-item Center for Epidemiological Studies–Depression Scale (CES-D; Radloff, 1977). This well-validated measure provides extensive normative data and clinical cutoff scores (scores greater or equal to 16 McLennan et al., 2001). Reliability was estimated using internal consistency (coefficient α); for this sample, α was .88 for caregivers of children with T1D and .89 for caregivers of children with CF.

Disease-specific Stress

The 15-item Family Stress Scale (FSS) was developed for CF populations (Quittner et al., 1998, Quittner, Opipari et al., 1992), and has been shown to be sensitive to illness-related stress. CF-specific items were adapted for use with caregivers of children with T1D for the current study by changing the content (e.g., ''Explaining CF to your child'' was changed to ''Explaining diabetes to your child''). The FSS assesses general (e.g., discipline) and disease-specific stress (e.g., doing treatments such as insulin injections, eating more calories) and respondents are asked to rate each item in the context of having a child with T1D or CF. A total score is derived and ranges from 0 to 60, with higher scores indicating higher levels of family stress. The FSS demonstrated good reliability, with high internal consistency estimates for both disease groups ($\alpha = .90$ for T1D and .80 for CF).

Health Status Variables

Health status variables differed between the two illness groups. All variables were obtained by reviewing the children's medical records. For children with T1D, hemoglobin A_1C (A1C) represents the average glucose level during the past 2.5 to 3 months (Blanc, Barnett, Gleason, Dunn, & Soeldner, 1981). Higher A1C values indicate poorer glycemic control; values under 8.0 represent good glycemic control in children (American Diabetes Association, 2009). Health status variables such as lung functioning were more difficult to obtain for children with CF because children younger than 7 years are generally unable to reliably complete this test. However, standardized body mass index (zBMI) is a widely accepted measure of health in young children with CF and was used as the indicator of health status in this study (Stallings, Stark, Robinson, Feranchak, & Quinton, 2008). Standardized BMI was calculated using age- (to the nearest month) and sex-specific median, standard deviation, and power of the Box-Cox transformation (LMS method) based on national norms from the Centers for Disease Control (Kuczmarski et al., 2000). Lower zBMI indicates poorer health status. Because A1C and zBMI are measured on different metrics, to permit statistical analysis of the total sample, they were transformed into *z*-scores based on the current sample's mean and standard deviation in order to create a single index of health status; higher *z*-scores indicated poorer health status.

Procedure

Informed primary caregiver consent was obtained. Prior to randomization into two study conditions, all data reported here were obtained through questionnaires and review of the child's medical chart. HANDling Diabetes/CF was approved by the Florida State University, University of Florida, and University of Miami Institutional Review Boards. The recruitment rates were 95% and 76% for T1D and CF, respectively.

Statistical Analyses

Prior to conducting the analyses, rates of missing data were examined. There were minimal data missing from any individual study variable (0.5–3.6%) and no systematic patterns could be identified; therefore, it is likely that the data were missing at random (Rubin, 1976). Consequently, multiple imputation was used in all analyses to generate appropriate parameter estimates. These estimates were generated using the Proc MI and Proc MIANALYZE procedures available from SAS 9.1 (SAS Institute, 2004).

Descriptive statistics were conducted to compare demographics between the two illness groups and estimate the rates of depression among female and male caregivers. Characteristics of the T1D and CF samples were compared using chi-square and independent samples *t*-tests. Potential risk factors of depression were identified using hierarchic multiple regression analyses. Predictor variables were entered in successive blocks. Because caregiver sex was not a significant predictor of depressive symptoms, the combined sample of female and male caregivers was used. Several demographic variables associated with depression in other studies were evaluated in the regression. In the first block, education ($0 = \leq$ high school, $1 \geq$ some college); race (0 = non-Caucasian, 1 = Caucasian); employment status (0 = not employed outside of the home, 1 = employed outside of the home); marital status (0 = not married, 1 = married); and age were entered. The second block consisted of child demographic variables: disease (0 = T1D; 1 = CF); sex (0 = female; 1 = male); and age. Insurance status (0 = public, 1 = private), an indicator of socioeconomic status and access to health care, was entered next. Child's health status (i.e., *z*-score) was entered next followed by the Family Stress

Scale scores, as stress has been shown to be associated with depression.

To determine if there were differences based on disease, interactions between disease and other variables in the combined model were considered. Because several of these interactions were significant, separate models for T1D and CF were evaluated. Duration of diabetes was added as a predictor variable in the separate model for T1D; however, duration of CF was not included in the CF model since it is confounded with age. Confidence intervals for differences between independent *R*'s were calculated (Cohen, Cohen, West, & Aiken, 2003, p. 88) to determine if there was a significant difference between the T1D and CF predictive models. All models were re-analyzed using logistic regression to predict above and below the clinical cutoff for depression.

Results

Sample Characteristics

Caregivers of children with T1D reported experiencing comparable levels of depressive symptoms ($M = 12.51$; $SD = 9.51$) to caregivers of children with CF ($M = 12.01$; $SD = 9.35$). The percentage of caregivers reporting symptoms above the clinical cutoff (≥ 16) was also comparable for the two groups of caregivers (T1D = 33.3%; CF = 32.2%). All other caregiver characteristics are found in Table I. Children with CF ($M = 6.34$ years; $SD = 3.06$) were significantly younger than children with T1D [$M = 8.14$ years; $SD = 2.47$; t (193) $= 4.56$, $p < .001$]. In addition, more children with CF had public insurance (54%), whereas more children with T1D had private insurance (61%; $\chi^2 = 4.45$; $p < .05$). There were no significant differences on any of the other demographic variables.

Predictors of Depressive Symptoms in Primary Caregivers

First, a regression model with the combined sample of primary caregivers of children with T1D or CF was analyzed. Main effects of lower education and higher family stress were associated with higher depression. However, the child's diagnosis interacted with child age, primary caregiver employment status, and health status (p's $< .05$). Consequently, the regression models were re-analyzed, one for primary caregivers of children with T1D and the second for primary caregivers of children with CF (Table II).

The best predictors of depressive symptoms for primary caregivers of children with T1D were lower caregiver education level, higher family stress, older child age, and poorer child health status as measured by A1C (Table II). The best predictors of depressive symptoms for primary caregivers of children with CF were higher family stress and lack of employment outside of the home.

Although the T1D model explained more variance than the CF model, the difference in the amount of variance explained by the regression models in both groups was not significant (Cohen et al., 2003). All models were re-analyzed using logistic regression with CES-D clinical cutoff scores (i.e., dichotomously coded as scoring either above or below the clinical cutoff). A similar pattern of results emerged; therefore, only multiple regression results are reported here.

Discussion

To our knowledge, this is the first study to examine risk factors associated with depressive symptoms among caregivers of children with T1D or CF. Approximately 33% of primary caregivers in our study experienced clinically elevated rates of depressive symptoms with no differences in rates between primary caregivers of children with T1D as compared to primary caregivers of children with CF. For caregivers of children with T1D, lower education, greater family stress, older children's age, and poorer glycemic control were associated with greater caregiver depressive symptoms. Although greater family stress was also associated with greater depressive symptoms among caregivers of children with CF, lack of employment outside of the home was the only other significant predictor of depressive symptoms.

For caregivers of children with T1D, rates of depressive symptoms in this study were similar to rates reported in some studies (Kovacs et al., 1990), but higher than rates in other studies (22% in Jaser et al., 2007 and 17% in Horsch et al. 2007), which may be attributed to greater numbers of children with poor glycemic control in the current study or differences in the measures used to assess depressive symptoms. Elevated rates of depressive symptoms in our CF sample were comparable to other studies involving caregivers of children with CF (Quittner et al., 1998), but lower than a more recent study of caregivers of young children recently diagnosed with CF (Glasscoe et al., 2007).

Depressive symptoms did not differ between female and male caregivers, which contradicts previous studies in both T1D and CF that found higher rates of depressive symptoms among female caregivers (Glasscoe et al., 2007; Kovacs et al., 1990; Quittner, DiGirolamo, Michel, & Eigen, 1992; Quittner, Opipari et al., 1992). The low number of male caregivers in the current study clearly

Table I. Sample Characteristics

Variable	T1D *N* (%) or M (*SD*)	CF *N* (%) or *M* (*SD*)	Test statistic
Caregiver demographics			
Age (years)	37.64 (8.35)	36.61 (8.40)	$F = .074$
Sex			$\chi^2 = .62$
Female	90 (83.3%)	76 (87.4%)	
Male	18 (16.7%)	11 (12.6%)	
Race			$\chi^2 = 2.83$
Caucasian	92 (85.2%)	79 (90.8%)	
Non-Caucasian	16 (14.8%)	6 (6.9%)	
Education			$\chi^2 = .001$
≤High school	40 (37%)	32 (36.8%)	
≥ Some college	68 (63%)	55 (63.2%)	
Work Outside of Home			$\chi^2 = 3.17$
No	27 (25%)	32 (36.8%)	
Yes	81 (75%)	55 (63.2%)	
Marital Status			$\chi^2 = .328$
Not Married	29 (26.9%)	20 (23.3%)	
Married	79 (73.1%)	66 (76.7%)	
Child demographics			
Age (years)	8.14 (2.47)	6.34 (3.06)	$t = 4.56$***
Child's Sex			$\chi^2 = .570$
Female	58 (53.7%)	45 (51.7%)	
Male	50 (46.3%)	42 (48.3%)	
Health Insurance Status			$\chi^2 = 4.45$*
Public	42 (38.9%)	47 (54%)	
Private	66 (61.1%)	40 (46%)	
Disease-related			—
Disease duration (years)	3.90 (2.61)	—	
A1C	8.30 (1.14)	—	
zBMI	—	0.01 (1.03)	
Family Stress Scale CES-D	30.42 (9.93)	31.05 (8.75)	$F = 1.575$
All caregivers			$F = .010$
Total Score	12.51 (9.51)	12.01 (9.35)	
CES-D < 16	72 (66.7%)	59 (67.8%)	
CES-D ≥ 16	36 (33.3%)	28 (32.3%)	
Female caregivers			$\chi^2 = .258$
Total Score	12.92 (9.62)	12.36 (9.18)	
CES-D < 16	57 (63.3%)	51 (67.1%)	
CES-D ≥ 16	33 (36.7%)	25 (32.9%)	
Male caregivers			$\chi^2 = .468$
Total Score	10.44 (8.85)	9.64 (10.69)	
CES-D < 16	15 (83.3%)	8 (72.7%)	
CES-D ≥ 16	3 (16.7%)	3 (27.3%)	

Note. T1D, type 1 diabetes; CF, cystic fibrosis; CES-D, Center for Epidemiological Studies-Depression Scale; A1C, hemoglobin A1C; zBMI, standardized body mass index.
*$p < .05$; ***$p < .001$.

limited our ability to detect differences between female and male caregivers. However, the male caregivers in this study were fulfilling primary caregiver roles. This is an important distinction from prior studies and suggests that the role may be an important contributor to depressive symptoms. Previous work has found significant differences in role functioning among parents of children with CF, and related these differences to increased levels of stress (Quittner, Opipari, et al. 1992). Thus, future studies are needed to better understand the relations between caregiver roles and depressive symptoms in caregivers of children with chronic illness.

Table II. Predictors of Caregiver Depressive Symptoms

Variable	β	T	p	sr^2	Adjusted R^2
Regression Model for T1D (*N* = 108)					
CES-D					.26***
Education level	−.20	−2.56	.012	−.197	
Family Stress Scale	.50	6.52	.000	.500	
Child's age	.21	2.72	.008	.209	
Works outside home	.08	1.01	.317	.077	
Child's health status (A1C)	.21	2.70	.008	.207	
Regression Model for CF (*N* = 87)					
CES-D					.24***
Education level	−.10	−1.05	.298	−.119	
Family Stress Scale	.45	4.72	.000	.476	
Child's age	−.01	−0.06	.955	−.006	
Works outside of home	−.36	−3.84	.000	−.403	
Child's health status (zBMI)	.18	−1.92	.059	.215	

Note. T1D, type 1 diabetes; CF, cystic fibrosis; CES-D, Center for Epidemiological Studies-Depression Scale; A1C, hemoglobin A1C; zBMI, standardized body mass index.
***$p < .001$

Primary caregivers of children with T1D who had lower levels of education were more likely to report depressive symptoms, which is consistent with prior studies (McLearn et al., 2006; McLennan et al., 2001). Although this link was not significant for the primary caregivers of children with CF, the association was in the expected direction (i.e., lower education associated with more depressive symptoms) and the model that combined both illness groups found no difference between groups in the magnitude of this association. A larger sample of primary caregivers of children with CF may have resulted in a significant finding.

Consideration of disease-specific risk factors for caregiver depressive symptoms may be important. Consistent with prior research demonstrating a link between increased depressive symptoms and stress (Stroud, Davila, & Moyer, 2008), the results of this study found that more T1D- or CF-specific stress was associated with increased levels of depressive symptoms in primary caregivers. Several recent studies of caregiver stress have emphasized the importance of assessing disease-specific stress (Streisand, Braniecki, Tercyak, & Kazak, 2001; Streisand et al., 2005) and to our knowledge, this is the first study to do so in a T1D sample. Studies using the Family Stress Scale with caregivers of children with CF reported comparable levels of stress (Quittner et al., 1998, Quittner, Opipari et al., 1992). In addition, health status may be an important risk factor. Despite using the best available health status indicator for each disease (i.e., A1C in T1D and zBMI for CF), they do represent different health outcomes. Although several previous studies did not demonstrate a specific link between caregiver depressive symptoms and children's glycemic control (Jaser et al., 2008; Kovacs et al., 1990), to our knowledge, the current study is the first to document a positive association. In contrast, the association between zBMI and primary caregiver depressive symptoms in the CF sample was not significant. It remains to be seen whether other measures of health status in this population, namely lung functioning or number of pulmonary exacerbations, are associated with depression in caregivers of young children with CF.

An important limitation of the current study is that it was designed to test an adherence intervention, not to identify risk factors associated with depressive symptoms in caregivers. In addition, the cross-sectional nature of the study limits our ability to draw conclusions about the course of depressive symptoms and the directional nature of the association found between primary caregiver depressive symptoms and demographic characteristics, stress levels, and child's health status. For example, the nature of the relation between child health status and caregiver depressive symptoms is unclear (i.e., Does poor glycemic control lead to depressive symptoms or vice versa?). Further, the restricted age range, relatively small sample of children with each disease, and the greater number of caregivers of children with CF who declined participation may limit the generalizability of this study; therefore, replication of our findings is necessary. In addition, the association between older child age and greater caregiver depressive symptoms might have been stronger, especially for caregivers of children with CF, if caregivers of adolescents had been included. Glycemic control and lung functioning decline during this period, which may lead to increases in depressive symptoms among caregivers. The number of male primary caregivers was relatively small as compared to female caregivers. Additional studies that include a larger number of male primary caretakers are necessary to fully understand the impact of chronic illness on caregivers. This study did not evaluate depressive symptoms in children old enough to provide self-reports, which may be important to consider since children of caregivers with depression are at greater risk for developing depressive symptoms themselves (Beardslee et al., 1996, 1998). Finally, this study used a questionnaire measure of depressive symptoms, not a diagnostic interview, and we did not examine all possible risk factors associated with depressive symptoms such as prior history of depression and sources of social support (Kendler, Myers, & Prescott, 2005).

In summary, these findings are clinically relevant and suggest that primary caregivers of children with T1D or CF experience significant elevations in depressive symptoms. It is possible that families who declined participation experienced more depressive symptoms or stress than those families who consented, particularly in caregivers of children with CF. Therefore, routine screening of depressive symptoms in all caregivers of children with chronic illness would be consistent with the U.S. Preventive Services Task Force's (USPSTF, 2002) recommendations that all adults be screened for depression and referrals for comprehensive assessment and intervention could be provided. In fact, Driscoll and colleagues (2009) demonstrated that screening for caregiver depression in a CF Clinic is possible and practical. In their study, the CF social worker administered a brief screening measure to the caregiver, which was immediately scored. If symptoms were elevated, referrals for intervention were provided. A similar approach could be used in diabetes clinic on an annual or biannual basis. Finally, the results of this study suggest some risk factors for caregiver depressive symptoms occur across populations (e.g., education level and stress), but that each population has additional unique risk factors. Recognition of disease-specific risk factors associated with the development of caregiver depressive symptoms will guide clinical care and the design of future intervention trials.

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