PARENT META-EMOTION PHILOSOPHY AND TRAJECTORIES OF CAREGIVING STRESS IN CAREGIVERS OF CHILDREN WITH CANCER

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Abstract

Parent Meta-Emotion Philosophy and Trajectories of Caregiving Stress in Caregivers of Children with Cancer

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Caregivers of children with cancer are at risk for numerous negative psychological outcomes, including elevated caregiving stress (CS). Different approaches to managing negative emotions that arise during cancer treatment as outlined in the framework of Parent Meta Emotion Philosophy (PMEP) may help explain caregivers' experience of CS. This paper aims to 1) characterize the course of CS over time and 2) identify PMEP factors that are associated with lower levels of CS and trajectories of decreasing CS. Participants were primary caregivers of 159 families of children aged 2-17 who were recently diagnosed with cancer. Caregivers completed a measure of CS at 1, 6, and 12-months post-diagnosis, and a subset (*n*=110) completed PMEP interviews roughly 3 months post-diagnosis. Growth models conducted using multilevel modeling (MLM) showed that CS tends to be highest immediately following diagnosis and decline over time, however there is considerable individual variability in the level CS at one-year post-diagnosis and its rate of change over time. Additionally, PMEP dimensions predicted CS, such that caregivers who were more accepting/regulating and had lower awareness of negative emotions generally reported lower CS at one year. Results suggest that primary caregivers may benefit from screening for elevated CS immediately following diagnosis as well as early intervention to teach strategies for acceptance and regulation of negative emotions.

Introduction

Patterns of stress and psychological maladjustment are well-documented among caregivers of children who are diagnosed with cancer (Katz et al., 2018; Pai et al., 2007; Patiño-Fernández et al., 2008; Sultan, Leclair, Rondeau, Burns, & Abate, 2016). Such difficulty makes sense given the sudden influx of new stressors and responsibilities associated with caring for a child with a complex medical illness, particularly one of a life-threatening nature. Caregiving stress (CS) is multifactorial in origin; it can include the emotional toll of worrying about treatment success, making medical decisions, communicating with a child's care team, financial strain, and balancing preexisting obligations such as work/school and caring for other family members (Patterson, Holm, & Gurney, 2004; Rodriguez et al., 2012; Streisand, R., Braniecki, Tercyak, & Kazak, 2001). High caregiving stress at the time of diagnosis may be normative, however a subset of caregivers likely experience elevated stress for years following diagnosis (Vrijmoet-Wiersma et al., 2008). Little work has looked at CS over time, including what factors may be associated with either the decline or maintenance of stress over the course of treatment.

Caregiving Stress in the First Year of Cancer Treatment

CS is an important outcome to examine in families of children with cancer because it negatively affects adjustment of parents (Streisand, R. et al., 2001; Sulkers et al., 2015), adjustment of ill children and the quality of their medical care (Colletti et al., 2008; Fedele, Mullins, Wolfe-Christensen, & Carpentier, 2011; Roddenberry & Renk, 2008), and family functioning in general (Streisand, Randi, Kazak, & Tercyak, 2003). Specifically with regard to caregivers of children with cancer, CS reported over the first year of cancer treatment accounted for 53% and 47% of the variability in depressive and anxiety symptoms, respectively (Sulkers et al., 2015); thus caregiver stress may be a critical treatment target for developing interventions to

support caregivers of children with cancer (Cousino & Hazen, 2013).

With a few notable exceptions (Fedele et al., 2011; Sulkers et al., 2015), little work has focused on the trajectory of CS over time, which is critical information for the timing of potential interventions. Previous work has found that CS is highest at time of diagnosis and declines on average over time (Fedele et al., 2011; Sulkers et al., 2015), paralleling patterns of adjustment found across other psychological outcomes in caregivers of children with cancer (e.g., Katz et al., 2018). However, by focusing on average trajectories, these methodologies neglect to capture individual variability in the course of CS. While CS improves for most caregivers, a subgroup of caregivers may be at risk for prolonged difficulty. To better target and support caregivers at risk for trajectories of elevated stress, we must first model and unpack this variability.

Predictors of Caregiving Stress

Research on factors that may exacerbate or relieve caregiving stress over the course of treatment is limited. Demographic factors such as being a single-parent and having only one child are linked to higher CS (Sulkers et al., 2015). Additionally, child health difficulties such as higher activity limitation (Litzelman, Catrine, Gangnon, & Witt, 2011) and more frequent/intense child pain (Anthony, Bromberg, Gil, & Schanberg, 2011; Barakat, Patterson, Daniel, & Dampier, 2008) have been linked to high caregiver stress in pediatric cancer or other pediatric illness populations.

Instead of attempting to change or minimize stress, appraisal of stressful events may be an important mechanism for reducing CS given that many of the stressful aspects of cancer are unmodifiable realities of the cancer experience (Cousino & Hazen, 2013). General literature on risk and resilience has largely focused on appraisal of external events (e.g., Lazarus's Appraisal Theory, Lazarus & Folkman, 1984), but appraisal of internal events, such as negative emotions,

may similarly have implications for adjustment (Goldman, Kraemer, & Salovey, 1996; Salovey, Stroud, Woolery, & Epel, 2002). Salovey and colleagues (2002) established that emotion appraisal skills related to how people to attend to, discriminate between, and regulate moods were generally associated with better adjustment outcomes (i.e., lower depression/social anxiety/physical symptoms, higher self-esteem). In particular, since cancer is an experience that brings up significant negative emotions for caregivers (Patterson et al., 2004; Vrijmoet-Wiersma et al., 2008), understanding how parents appraise and respond to negative emotions resulting from cancer and treatment may explain what leads parents to experience the various aspects of caregiving as either more or less stressful. While some prior work has investigated one's approach to emotions as a resilience factor through adversity (Goldman et al., 1996; Salovey et al., 2002), this remains unstudied in pediatric cancer or amongst caregivers.

Parent Meta-Emotion Philosophy

Gottman and colleagues (1996) described a framework for conceptualizing how parental appraisal of negative emotions functions in families; Parental Meta-Emotion Philosophy (PMEP) examines parents' attitudes toward their own and their child's negative emotions (i.e., sadness, fear, and anger), including how parents recognize, respond to, and think about the role of emotions in their daily lives. Three core dimensions of PMEP are awareness, acceptance, and regulation of negative emotions. Parents high in these dimensions pick up on their own low-level negative emotions and distinguish between different emotions; they see negative emotions as part of life—they have value and should be recognized as opportunities for growth; and importantly, they also have strategies for effectively managing negative emotions. PMEP has been linked to several child outcomes, including internalizing and externalizing problems, social and academic competence, self-esteem, and physical health (see Katz, Maliken & Stettler, 2012

for a review), however links between PMEP and parent adjustment outcomes remain understudied. Specifically, no work has examined PMEP as it informs domains of parent/caregiver stress.

The Current Study

Research has demonstrated that CS is an important piece in understanding the experiences of caregivers of children with cancer that has implications for broader caregiver, child, and family adjustment. Given gaps in the existing literature, the first aim of the current study was to describe the average course and variability in caregiving stress measured at three timepoints over the first year of treatment. We hypothesized that CS would decrease on average over the first year of treatment, but that variability would exist among caregivers in reported levels of CS at one year and in how CS changes over time. The second aim of the study was to investigate PMEP as a potential factor that predicts variability in trajectories of CS over time. We hypothesized that caregivers who were more aware, accepting, and regulating of their own negative emotions would report lower levels of CS at one year and decline more rapidly in CS than other caregivers. By better understanding which caregivers are at greatest risk for elevated CS and when, we can optimize the targeting and timing of interventions to better support caregivers and their families.

Method

Participants

The present study included 159 families of children aged 2-17 (M = 6.31, SD = 3.54 years, 48% male, 85% White) who were diagnosed with cancer. Cancer diagnoses consisted of leukemia (37%), CNS malignancies (30%), lymphoma (11%), and other types of solid tumors (31%). The majority of families identified mothers as the primary caregiver (86%), with some

identifying fathers (11%), or other adults (3%) like grandparents or step-parents. Primary caregivers were on average 36.45 years old (SD=7.98), and most were white (85%), married (78%), and had completed some post-secondary education (72%). Family incomes were widely distributed, with median income between $60,000 and $69,000.

Procedures

Families were contacted as part of a larger study of family conflict and adjustment conducted at two major children's hospitals in the U.S. In eligible families, participants were English-speaking, the child did not have a history of developmental delay, and the current caregivers also cared for the child prior to diagnosis. Participants were excluded if the child was diagnosed with NF1 or the cancer diagnosis was a relapse or secondary malignancy. Of the 502 families eligible for participation across both sites, 309 were approached, 176 enrolled, with 159 completing at least one study component. Of the families approached who did not enroll, refusal was due to either excessive time required or no reason was given.

First contact with families occurred within two weeks of diagnosis, and families participated by completing a combination of mailed questionnaires and phone interviews throughout the first year following diagnosis. Questionnaire data included for this manuscript were collected at 1-, 6-, and 12-months post-diagnosis (T1, T6, T12). Of families enrolled, 69% of primary caregivers (*n*=110) completed PMEP interviews, which were conducted at approximately 3 months post-diagnosis.

Measures

Caregiving Stress. The Pediatric Inventory for Parents (PIP; Streisand, et al., 2001) specifically assesses stress associated with caring for a child with a medical illness. It has previously been used and validated with parents of children with cancer and found to account for

a significant amount of the variability in overall parent anxiety (Streisand, et al., 2001). The measure includes 42 Likert scale items encompassing stressful events that fall into the subscales of Communication, Emotional Distress, Medical Care, and Role Function. While these items on the PIP can be scored according to either frequency or difficulty, we chose to focus on difficulty to capture variability in the subjective experience of stress associated with caring for a child with cancer. Caregivers were asked how difficult events had been over the past month and prompted to answer between 1 = "Not at all" and 5 = "Extremely." Difficulty scores were summed separately for each of the four subscales. Internal consistency for this measure was high, with Cronbach's alphas for each subscale ranging from α=.80-.96.

Parent Meta-Emotion Philosophy. The Parent Meta-Emotion Interview (PMEI; Katz & Gottman, 1986) assesses parent attitudes toward their own and their child's negative emotions. For the purpose of this study, we focus on how parents respond to their own emotions, specifically looking at the dimensions of awareness, acceptance, and regulation of negative emotions. The PMEI asks questions tapping how parents think about their negative emotions as well as the specific actions they take to respond to these emotions. Primary caregivers completed phone interviews that lasted approximately 45 minutes. Interviews were coded using the Revised Meta-Emotion Coding System (Hunter et al., 2006), which yields subscales for parental awareness (9 items), acceptance (4 items), and regulation (6 items) of negative emotions. All items were independently coded by research assistants on a 5-point Likert scale, and summed to create composite subscale scores. Interrater reliability and internal consistency for this interview and scoring system have been previously established, with interrater reliability ranging from r=.65-.91 across different subcales (Katz & Hunter 2007). The current data represent preliminary data for which estimates of reliability are not available, however rates of internal consistency

were acceptable and ranged from α=.68-.92

Data Analytic Strategy

Descriptive characteristics and attrition analyses were conducted in SPSS Version 19. All further analyses were conducted in R Studio. Multilevel models (MLM) were used to examine trajectories of CS over time. These models are used to examine non-independent data, such as repeated measures nested within individuals. MLM models allow for different numbers of observations for each individual, which allowed us to use data from caregivers who did not provide data at every timepoint.

For Aim 1, linear growth curve models were created to model the average within-person trajectory of each domain of CS across the first year of treatment (fixed effects) and between-person variability in these trajectories (random effects), with the intercept modeled at T12. For Aim 2, PMEP subscales were independently tested as predictors of variability in each domain of caregiving stress over time. Specifically, we tested whether each PMEP subscale was associated with the rate of change in CS over time and level of CS at the final time point (T12).

Results

Aim 1: Growth Models of CS

Linear growth models indicated that each of the four subscales of CS declined over the course of the first year of cancer treatment (see Table 1 for growth model fit indices). Including random effects for both the intercept and slope improved model fit for Communication, Emotional Distress, and Role Function models, meaning that caregivers varied significantly in their rate of change in CS and in their level of stress at the end of one year. Regarding Medical

Care, model fit was improved by including a random effect for the intercept but not the slope, meaning that there was significant variability in the level of Medical Care stress at the end of one year, but the rate by which Medical Care CS decreased was fairly consistent between caregivers. Random effects for both the slope and intercept parameters for most CS subscales indicated variability between families, thus justifying an investigation of potential factors that may explain variability in trajectories of CS.

Aim 2: PMEP Predicting Trajectories of CS

PMEP dimensions (Awareness, Acceptance, Regulation) were added as predictors to final models to test whether they helped further explain the course of caregiving stress for parents, as indicated by statistical significance and improvement in model fit (see Table 2). In contrast to hypotheses, higher Awareness predicted higher Emotional Distress at one year. Caregivers who reported being more aware were the ones who reported more Emotional Distress. Additionally, there was a marginally significant interaction effect, suggesting that highly aware parents report increasing Emotional Distress over time relative to parents who are less aware of negative emotions. Higher Acceptance predicted lower Emotional Distress and lower difficulty with Medical Care at one year. Finally, better regulation of negative emotions predicted lower difficulty with Communication, lower Emotional Distress, and lower difficulty with Medical Care at one year. Beyond the single marginal effect for Awareness predicting increasing Emotional Distress, no evidence was found for PMEP x Time interaction effects. Additionally, no evidence was found for PMEP dimensions predicting CS from difficulty in Role Function.

Discussion

Consistent with prior literature (Sulkers et al., 2015), the data showed that CS tends to be highest immediately following diagnosis and decline over time. Findings added novel contributions by demonstrating that there is considerable individual variability in the trajectory of CS between families. Additionally, PMEP dimensions distinguished which caregivers experienced more difficulty from CS, such that caregivers who were more accepting of negative emotions, had better regulation strategies, and reported lower awareness of negative emotions generally reported lower CS.

Significant fixed and random effects of intercept and time demonstrated that caregivers varied significantly with regard to how CS changed over the first year as well as final levels of experienced CS. It was initially surprising that random effects for slope were included in final models for all CS subscales with the exception of Medical Care; however, this may be an encouraging finding, because it suggests that families may be adapting to the difficult aspects of complex medical care across the board. Parents often report feeling overwhelmed by the daunting task of mastering a completely new language of medical terminology and repertoire of caregiving skills. However, regardless of initial levels of reported stress associated with medical care, caregivers consistently report declines in stress as they gain experience.

Given extant literature on meta-emotion strategies, we hypothesized that higher awareness, acceptance, and regulation strategies of negative emotions would be adaptive. For example, previous research has found that being able to better identify and describe emotions (i.e., awareness) is actually predictive of better adjustment outcomes (Ciarrochi & Scott, 2006). Thus, we did not expect that caregivers who were more aware of negative emotions reported higher stress scores. It remains unknown whether this is just a response style among caregivers (i.e., that those who are more cued into negative emotions are simply more likely to endorse

stress) or whether awareness is actually harmful in this context. It may be that in the case of an uncontrollable stressor such as pediatric cancer, greater awareness of negative emotions might increase distress in the form of emotional experiencing and rumination without inspiring any positive outcomes, such as problem solving. Future research may endeavor to test nonlinear associations to understand whether there is an "optimal" level of awareness such that parents can successfully label and respond negative emotions but are not overly attentive or sensitive to negative emotions. A pattern of extremely high awareness may actually reflect the post-traumatic stress symptoms of hyperarousal and intrusive thoughts that are well documented among parents of children with cancer (Dunn et al., 2012; Kazak, Boeving, Alderfer, Hwang, & Reilly, 2005; Vrijmoet-Wiersma et al., 2008). It is additionally possible that higher awareness is not a risk factor in it of itself, but only when paired with the absence of regulation strategies. Interactions between PMEP dimensions may be an important direction for future exploration.

Consistent with expectations, parents who were more accepting of negative emotions reported lower CS. As previously stated, cancer is largely an uncontrollable stressor. Many of the difficult aspects of a life-threatening child illness cannot be ameliorated simply by employing better problem-solving skills. As such, coping research in pediatric cancer has demonstrated the importance of secondary control coping (Compas et al., 2014; Compas et al., 2015). In contrast to primary control coping strategies, which focus on changing the stressor or one's emotional response (e.g., problem-solving, emotion modulation), secondary control coping refers to adapting to the stressor. Acceptance, along with cognitive reappraisal, distraction, and positive thinking, are key secondary control coping skills. Thus acceptance, not only of stressful aspects of childhood cancer and treatment, but also of the associated negative emotions may similarly influence the adjustment and subjective distress of caregivers.

Finally, regulation of negative emotions was the most consistent predictor of lower CS across different domains of stress. This is logical given the robust literature on emotion regulation as a transdiagnostic factor underlying the development of many aspects of stress and psychopathology. Specifically, a review from Rutherford and colleagues (Rutherford, Wallace, Laurent, & Mayes, 2015) outlines the manifold ways emotion regulation skills manifest during parenthood and are critical for adjustment of both parent and child. A caregiver's successful regulation of negative emotion serves to decrease emotional distress in the moment, which has positive implications for their capacity as attentive and consistent caregivers, and additionally serves as a powerful model of effective regulation strategies for children and other family members. Beyond normative parenting contexts (if it can be argued that there is such a thing as a "normative parenting context"), our data suggests that regulation is similarly important in the extraordinary circumstance of parenting a child with cancer. Very limited work has previously examined implications emotion regulation processes in caregivers of children with cancer, but one qualitative investigation has highlighted the importance of emotion regulation for the health of the parental dyadic relationship (Koivula, Kokki, Korhonen, Laitila, & Honkalampi, 2019). Additionally, another study found that caregivers exerted notable social influence on children's emotion regulation (Firoozi, Besharat, & Rahimian Boogar, 2013). Future work should further examine emotion regulation in caregivers as it relates to individual and family-level adjustment.

This study represents an important step in understanding the CS experiences of caregivers of children with cancer, however it is still important to recognize several limitations that should be addressed in future research. First, while the participants were recruited from two separate sites in the US, they were mostly White and of high socioeconomic status (SES). Thus findings may not capture the experiences of individuals from diverse ethnic and racial backgrounds or

those in lower SES contexts, wherein individuals may be more likely to experience greater stress associated with caring for a child with cancer (Bemis et al., 2015). Additionally, this study focused on the primary caregivers, and results may not generalize to secondary caregivers or fathers. Given that fathers and mothers typically take on distinct roles in cancer care (McGrath, 2001; Nicholas et al., 2009; Nicholas, Beaune, Barrera, Blumberg, & Belletrutti, 2016), stress associated with those tasks may look different from that of primary caregivers. It is also worth noting that PMEP was not evaluated at the time of enrollment in the study, but two months later, thus it is unknown whether the timing of these data capture parents' strategies for dealing with emotions directly following their child's diagnosis. PMEP is theorized to be a trait-like characteristic, but no prior research has examined whether it may change in response to an acute stressor such as childhood cancer.

Even in light of study limitations, this work still holds several implications for clinical practice. Primary caregivers, who typically demonstrate the poorest adjustment of anyone following a child's cancer diagnosis, even the child himself (Katz et al., 2018; Sultan et al., 2016; Vrijmoet-Wiersma et al., 2008), may benefit from brief interventions teaching skills for acceptance and regulation of negative emotions. Given that caregivers are experiencing the highest CS at the time of diagnosis, potential interventions ought to be delivered early in treatment for maximum effect. Following diagnosis is also the most hectic time for caregivers, so potential interventions should be brief, targeted, and thoughtfully delivered in tandem with other medical care. Ultimately, we may increase positive adjustment in caregivers by training mental health professionals in the hospital setting to 1) screen for high CS among caregivers, and 2) teach caregivers acceptance and regulation skills to employ as negative emotions arise.

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Table 1. Growth Model Building and Final Parameter Estimates

	AIC	Int. *b* (SE)	Var(Int.) σ^2	Slope *b* (SE)	Var(Slope) σ^2
Communication Difficulty					
1	2141.1	20.09 (.50)***	19.52	-	-
2	2088.8	16.61 (.67)***	21.60	-2.87 (.37)***	-
3	*2081.7*	*16.69 (.79)****	*45.61*	*-2.82 (.41)****	*7.30*
Emotional Distress					
1	2639.0	45.51 (1.02)***	65.03	-	-
2	2534.0	35.10 (1.33)***	83.37	-8.68 (.74)***	-
3	*2519.6*	*35.03 (1.64)****	*199.52*	*-8.70 (.85)****	*27.02*
Medical Care Difficulty					
1	2148.6	19.06 (.50)***	16.85	-	-
2	*2076.2*	*14.72 (.68)****.	*21.15*	*-3.57 (.38)****	-
Role Function Difficulty					
1	2322.3	24.95 (.63)***	27.02	-	-
2	2242.6	19.30 (.84)***	33.40	-4.68 (.47)***	-
3	2231.4	19.37 (1.03)***	77.98	-4.63 (.53)***	11.12

Note. Intercept *b* = estimate of average ending point; Intercept s^2 = variance in ending point. Slope *b* = estimate of average rate of change. Slope s^2 = variance in rate of change. Final models are italicized.

Table 2. Regression Coefficients for PMEP Dimensions Predicting Caregiving Stress

	Communication β(SE)	Emotional Distress β(SE)	Medical Care β(SE)	Role Function β(SE)
Awareness				
Time	0.036 (0.07)	-0.010 (0.71)	0.031 (0.07)	0.044 (0.07)
Awareness	0.245 (0.13)†	**0.258 (0.12)***	0.075 (0.11)	0.175 (0.12)
Time*Awareness	0.086 (0.07)	0.133 (0.07)†	0.027 (0.06)	0.109 (0.07)
Acceptance				
Time	0.031 (0.08)	-0.016 (0.07)	0.028 (0.07)	0.039 (0.07)
Acceptance	-0.236 (0.12)†	**-0.250 (0.12)***	**-0.251 (0.11)***	-0.147 (0.12)
Time*Acceptance	-.021 (0.07)	0.013 (0.07)	-0.067 (0.06)	-0.038 (0.07)
Regulation				
Time	0.035 (0.074)	-0.011 (0.07)	0.028 (0.07)	0.042 (0.07)
Regulation	**-0.300 (0.13)***	**-0.301 (0.12)***	**-0.251 (0.11)***	-0.176 (0.07)
Time*Regulation	-0.067 (0.08)	-0.041 (0.08)	-0.067 (0.06)	-0.012 (0.08)

Note. Standardized betas reported. * $p < .05$, † $p < .10$