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Putting on a Happy Face: Emotional Expression in Parents of Children with Serious Illness

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Abstract

Context—Communication is widely acknowledged as a crucial component of high-quality pediatric medical care, which is provided in situations where parents typically experience strong emotions.

Objectives—To explore emotion using both the LIWC and a self-report questionnaire to better understand the relationship between these two measures of emotion in a pediatric care context.

Methods—Sixty-nine parents of 47 children who were participants in the Decision Making in Pediatric Palliative Care Study at The Children's Hospital of Philadelphia took part in this study. Parents completed the Positive and Negative Affect Schedule (PANAS) and a semi-structured interview about their children and experience with medical decision making. The transcribed interviews were analyzed with the Linguistic Inquiry and Word Count (LIWC) program, which yields scores for positive and negative emotional expression. The association between LIWC and PANAS scores was evaluated using multivariate linear regression to adjust for potential confounders.

Results—Parents who used more positive words when speaking about their children's illnesses and the experience of medical decision making were more likely to report lower levels of positive affect on the PANAS: a standard deviation increase in positive emotional expression was associated with an unadjusted 7.6% decrease in self-reported positive affect (P=0.01) and an adjusted 10.0% decrease in self-reported positive affect (P=0.05) after modeling for potential confounders. A standard deviation increase in negative emotional expression was associated with an adjusted 11.3% increase in self-reported negative affect (P=0.04).

Conclusion—The inverse relationship between parents' positive emotional expression and their self-reported positive affect should remind both researchers and clinicians to be cognizant of the possibilities for emotional miscues, and consequent miscommunication, in the pediatric care setting.

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Keywords

Communication; caregivers; chronic disease management; emotion; palliative care

Introduction

Communication between parents and clinicians is widely acknowledged as a crucial component of high-quality care for children with serious pediatric illnesses. Parents rely on this communication in order to understand their child's medical condition, and can more effectively participate in decision making for their child's care once they are informed. These interactions occur, however, in a context of high parental stress and often outright distress. In order to improve parent-clinician interactions in these circumstances, clinicians need to understand the strong and seemingly contradictory feelings that parents experience in such situations so that clinicians can help parents participate more actively in shared decision making.[1-6]

Parents of children with life-threatening illnesses experience heightened positive and negative emotions simultaneously, as they may love and feel proud of their child while at the same time feel sadness and anger about their child's health prognosis.[7,8] Differences among individual parents regarding how they communicate emotions to clinicians (or researchers) are unknown; nevertheless, clinicians on a daily basis make assumptions about parents' emotional experiences based on a variety of behavioral and interpersonal cues combined with consideration of individual and situational factors. Because these assumptions about parental emotions may not correspond to parents' subjective emotions, the ensuing quality and effectiveness of communication and palliative care support may suffer.[9]

Measuring an individual's emotional state is complex and challenging. Multiple methods have been developed for assessing emotion, including self-report questionnaires, physiological measures, facial measures, and observer ratings. No "gold standard" exists[10]; each way of measuring emotion likely captures different aspects of a person's emotional experience and has its associated strengths and weaknesses. Self-report measures are widely used and easy to administer, but these measures assume that respondents have the ability to perceive and name their own emotions, and this ability has been shown to vary substantially among individuals.[11,12] Alternatively, recently developed computer-based linguistic word inquiry programs evaluate the verbal and written communication styles of individuals, categorizing words and phrases according to their affective valence as positive or negative and then tallying and compiling individuals' use of these words and phrases. One such program, the Linguistic Inquiry and Word Count (LIWC), developed by James W. Pennebaker, has been used in studies on emotional expression in adults in treatment for substance abuse,[13] women participating in online support groups for breast cancer,[14] linguistic styles in children with attention deficit hyperactivity disorder,[15] and other psychological research.[16-18]

When employed along with self-reported affect measures, the LIWC measures of emotional expression may provide additional information regarding how emotions are experienced and communicated by parents of children with serious pediatric illnesses. Whereas prior studies in adult patients with cancer have shown no association between the LIWC measures and self-report of positive and negative emotion,[19,20] the LIWC measures were associated with qualitative coders' ratings.[20] Because of this finding, Bantum and colleagues recommend using such measures of emotional expression as a supplement to self-report measures.[20] Therefore, in this study, we explore emotion using both the LIWC and a self-report

questionnaire to better understand the relationship between these two measures of emotion in a pediatric care context.

Patients and Methods

Sample

All parents were participants in the Decision Making in Pediatric Palliative Care Study at The Children's Hospital of Philadelphia.[7,21] The families of all children receiving both new and existing palliative care consults between October 2006 and July 2008 were screened for eligibility. Parents were eligible to participate if they were English speaking, older than 18 years of age, and if their child was either less than 18 years of age or 18 years of age or older but impaired cognitively and did not make personal medical decisions. Of 88 eligible families screened, 50 families (62.5%) consented to participate and were interviewed. When possible, a second parent was interviewed in addition to the primary parent. All interviews were conducted separately for each parent, and all participants received $25. Enrollment ended when the recruitment goal of 50 families was reached. In total, 73 parents of 50 children participated (i.e., 50 primary parents and 23 additional parents). Although most parents completed the interview and surveys in person, 17 parents (23.3%) participated via telephone and the Internet.

Data Collection

Parents completed several questionnaires and participated in a semi-structured interview about their child and their experiences with medical decision making. All interviews were conducted by the first and third authors. The interview began with the question, "Could you tell me about what has been significant to you about your child's illness?" and concluded with several open-ended questions about sources of support, religion and spirituality, hope, trust, and feedback on the interview itself. The interviews were audio-recorded and subsequently transcribed. Four parents were missing transcripts because of equipment malfunction during the recording of interviews. Therefore, 69 of 73 parents (95.4%) had transcripts available for analysis. Of these, 62 of 69 (89.9%) parents had complete information regarding self-reported affect.

Main Outcome Measure

Positive and Negative Affect Schedule (PANAS)—The well-validated PANAS[22,23] was used to measure parental self-reported affect. The PANAS contains a list of twenty adjectives that correspond to either positive (interested, alert, attentive, excited, enthusiastic, inspired, proud, determined, strong, and active) or negative (distressed, upset, guilty, ashamed, hostile, irritable, nervous, jittery, scared, and afraid) emotions. Parents were asked to rate how much they felt each emotion during the past week using a scale ranging from 1-very slightly to 5-extremely.

Main Predictor Measure

Positive and Negative Emotional Expression—We used LIWC software[24] to assess positive and negative emotional expression during the semi-structured interview. The comments of the interviewer were removed from the transcripts prior to analysis. Emotional expression was assessed by the frequency of positive emotion words (e.g., love, nice, sweet; 406 total positive words in the LIWC dictionary) or negative emotion words (e.g., hurt, ugly, nasty; 499 total negative words), divided by the transcript word count.

Parent and Child Demographic and Clinical Characteristics

Parent age was obtained through parental self-report and grouped into the following three categories: 21-34 years, 35-38 years, and 39-66 years. Parent type (Mom, Dad, and other), race (white, black, and other), relationship (married/partnered and other), and education (some high school or high school graduate, some college or college graduate, and some graduate school or graduate school graduate) were also obtained through parental self-report, as was child insurance (private, Medicaid, and low cost/limited/none).

Child age, gender, and diagnosis were obtained from the child's medical record. The child's diagnosis was classified according to an established complex chronic conditions coding scheme[25,26] into one of the following six categories: neuromuscular, metabolic, malignancy, congenital, respiratory, and gastrointestinal.

The child's illness trajectory, an established parent-reported measure of the child's health status,[7] was measured as the mean slope of a line plotted connecting the scores over five time points (one year ago, six months ago, one month ago, one week ago, and today) of the parents' perceptions of the child's health status (rated on a scale of 1-10); the slope of the resulting line represents the illness trajectory rate.

Statistical Analysis

The analysis aimed, a priori, to evaluate the relationship between positive and negative emotional expression (LIWC) and self-reported affect (PANAS) and to determine whether the observed association was the result of confounding. We report frequencies and percentages for parent and child characteristics. Univariate linear regression was used to determine the association between parent and child characteristics and positive and negative self-reported affect. We examined the effect of LIWC on PANAS measures in two multivariate regression models that account for the clustering of parents within families and provide corrected standard errors. These models also adjusted for observed confounders of the relationship between LIWC and PANAS using the change-in-estimate method described by Greenland.[27] This method includes covariates that might be potential confounders into the model in a step-wise fashion and considers variables that change the estimated effect of LIWC on PANAS by 10% (in either direction) to be confounders. The final adjusted model includes LIWC as well as all of the covariates identified as confounders.

To account for scattered missing data for parental age, race, and education, we imputed the missing values using imputation by chained equations using the analysis variables and an indicator variable for each family, to account for clustering of parents within families. To facilitate the interpretation of regression coefficients, positive emotional expression, negative emotional expression, and the illness trajectory measure were centered using z-score transformations. Similarly, self-reported positive and negative affect scores were log transformed so that the β coefficients could be interpreted in the form of percentage change. All analyses were performed in Stata 12.1 (StataCorp LP, College Station, TX).

Results

Our analytic sample consisted of 69 parents from 47 families. Parents participating in the study ranged in age from 21-66 years (mean 37.3 years, standard deviation [SD] 8.1 years). Whereas most parents who participated were mothers (59%), there were 25 (36%) fathers and three (4%) other participants (a stepmother, grandmother, and aunt) (Table 1). Because our results were not impacted by the inclusion of the three "other" parents, we retained them in the analysis. The majority of parents were white (71%), 15% were black, 7% of parents identified themselves as mixed or other, and 7% had an unknown race. Nearly three-quarters

(71%) of parents were married, and 68% had at least some college education. Positive and negative self-reported affect did not vary by parent characteristics (Table 1).

The majority of children were less than four years of age, with an age range of 0.02 to 24 years (mean 5.4, SD 5.7). Slightly more than half were female (51%), and 49% had Medicaid as their primary insurance. Children had a variety of complex chronic conditions, including neuromuscular (30%), metabolic (26%), malignancies (21%), congenital (15%), respiratory (4%), gastrointestinal (2%), and cardiovascular (2%). Parental positive and negative self-reported affect did not vary by child characteristics except for child age (Table 2). Parents of older children (5-9 years) had a significantly lower mean negative affect score than did parents of children less than one year old (24.3 vs. 31.7, respectively, P= 0.019).

Based on the regression results, parents who demonstrated more positive emotional expression during the semi-structured interview were significantly more likely to report lower levels of positive self-reported affect on the PANAS. A standard deviation increase in positive emotional expression was associated with an unadjusted 7.4% decrease in positive self-reported affect (P=0.015) and an adjusted 7.0% decrease in positive self-reported affect (P=0.057) after modeling for parent age, race, level of education, the child's insurance, illness trajectory, and whether or not the interview took place over the phone (Table 3).

Parents who demonstrated more negative emotional expression during the semi-structured interview were significantly more likely to report higher levels of negative self-reported affect on the PANAS. A standard deviation increase in negative emotional expression was associated with an unadjusted 6.1% increase in negative self-reported affect (P=0.18) and an adjusted 9.4% increase in negative self-reported affect (P=0.036) after adjusting for the same confounders mentioned above (Table 4).

There were no statistically significant associations observed between positive emotional expression and negative self-reported affect or negative emotional expression and positive self-reported affect. A standard deviation increase in negative emotional expression was associated with an unadjusted 1.7% increase in positive self-reported affect (P=0.51) and an adjusted 2.9% increase in positive self-reported affect (P=0.32) after modeling for parent age, race, level of education, the child's insurance, illness trajectory, and whether or not the interview took place over the phone. Similarly, a standard deviation increase in positive emotional expression was associated with an unadjusted −0.6% change in negative self-reported affect (P=0.87) and an adjusted 1.5% decrease in negative self-reported affect (P=0.77) after modeling for parent age, race, level of education, the child's insurance, illness trajectory, and whether or not the interview took place over the phone.

Discussion

Whereas negative emotional expression during a semi-structured interview was positively associated with self-reported negative affect in this sample of parents of children receiving palliative care, positive emotional expression was inversely associated with self-reported positive affect. In other words, parents who exhibited more positive emotional expression during a semi-structured interview were likely to have lower self-reported positive affect. This discrepancy between positive emotional expression and self-report of positive affect may generate communication misunderstandings or challenges in parent-clinician interactions.

What causes this discrepancy? And are parents consciously or unconsciously communicating verbal positive affect in excess of their self-reported positive affect? Four possible theoretical explanations may be applicable to both of these questions. First, parents may be trying to influence their own emotions by speaking more positively when they feel

less positive. This would be a form of emotional regulation, whereby speaking positively might serve to augment or intensify positive feelings for the parent.[28,29] This form of response or behavior also has been referred to as "deep acting," whereby a person tries to shape their emotional experience by expressing a particular affect.[30] (This is also suggested in the song "Put on a Happy Face" by Adams and Strouse from the musical "Bye Bye Birdie"). Of note – and consistent with our findings – although the sharing of positive emotion is thought to improve mood, the sharing of negative emotion has not been found to impact mood.[31] Other research had demonstrated an orthogonal relationship between positive and negative affect, in that the two types of affect are thought to be independent of and do not influence each other.[23,32,33] These findings may explain, in part, why different relationships are observed between positive emotional expression and self-reported positive affect, and negative emotional expression and self-reported negative affect (and the lack of association between positive emotional expression and self-reported negative affect, and negative emotional expression and self-reported positive affect).

Second, a parent's expression of affect may be shaped, wittingly or unwittingly, so as to conform with implicit "emotional display rules"[34] that parents perceive to be normative in the social situation of a hospital interview. Although the interviewers encouraged parents to speak freely about their experiences, the experience took place in hospital rooms; parents likely communicated differently with the interviewer than they would with family members or others in their private lives. Similar to employees who must manage their emotions on the job through "surface acting,"[30] parents may be accustomed to maintaining a certain level of positivity when interacting with hospital staff. In this situation, parents may be trying to be polite or influence the discussion to create a good impression or improve their access to medical personnel and other material support.

Third, parents who are acting out of love for their child also may want to minimize negative emotions and emphasize positive emotions in their communication with others out of a sense of loyalty and protectiveness to the child.[35] In other words, because parents have positive feelings for their child, they may speak more positively about their child's situation than their self-reported affect would suggest. Conceivably, talking negatively about a child's medical situation is perceived as a betrayal of trust for some parents. Similar patterns of loyalty have been observed in parents of adolescents with problem behaviors [36] and parents of children and young adults with characteristics of borderline personality disorder.[37]

Fourth, the results, in part, could be the result of potential bias introduced by the two different time frames for the PANAS (which asks respondents to recall over the past week) and the LIWC assessment (which analyzes only what was said during the interview), which could result in discrepancies in either direction (the prior week could have been emotionally more positive or negative than the time of the interview). Given the nature of scheduling interviews, which occurred at the convenience and wishes of the parent, the time of the interview would not have been in or shortly after a moment of medical crisis; conceivably, then, the parents may have recalled less positive affect during a preceding period of time than what they were experiencing at the time of the interview. Such a mechanism would affect not only metrics of this study, but would also potentially cause discrepant communication of affect in routine clinical communication during family meetings or bedside rounds, which also often are timed so as to avoid moments of medical crisis.

This study had several strengths and limitations. A major strength of this study is that interviews with parents were conducted while their children were still living, and, therefore, the effects of retrospective constructive memory and of the grieving process following the child's death did not influence the findings. Another strength is that we used an innovative, yet scientifically valid, way of expanding our understanding of emotion through use of the

LIWC program, while at the same time contrasting this method with the popular PANAS self-report instrument. The major limitation of this study is that it is an analysis of a cohort study on medical decision making in pediatric palliative care and the sample size may not have been large enough to demonstrate the statistical significance of certain associations. For these reasons, our findings should be generalized with caution, and focused instead on provoking further inquiry about the communication of emotional states by parents (as well as other family members, and by patients) and generating testable hypotheses.

The inverse relationship between positive emotional expression and self-reported positive affect in this population should remind both researchers and clinicians to be cognizant of the possibilities for emotional miscues, and consequent miscommunication, in the pediatric care setting. Future research should explore whether the discrepancy between positive emotional expression and positive self-reported affect are evident not only in spoken words but also in facial expressions and body language; whether such discrepancies occur for other emotional states and in other samples of subjects; whether clinicians can detect emotional state discrepancies in routine clinical practice; and the impact of these discrepancies on communication and decision making, and if found to be problematic, how to address these discrepancies.

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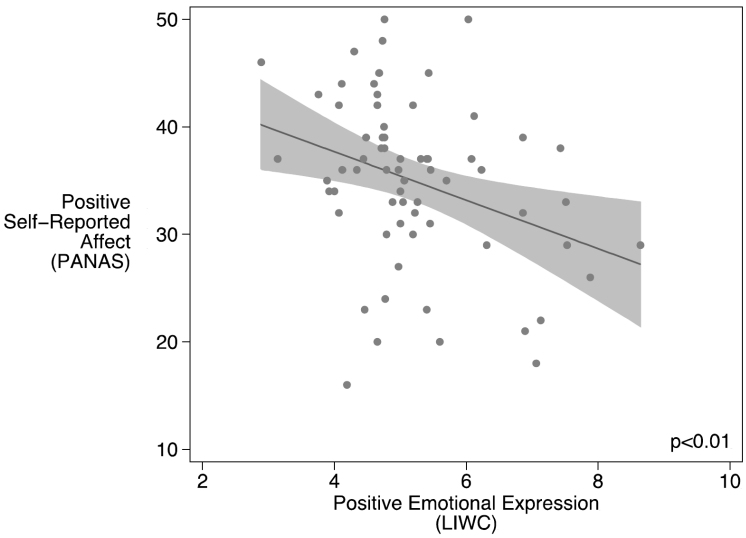

Fig. 1.

The relationship between positive emotional expression and positive self-reported affect, with 95% confidence interval.

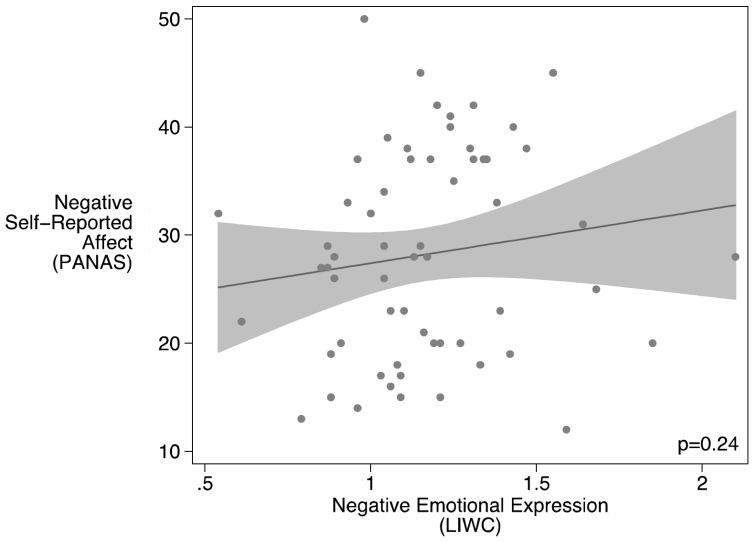

Fig. 2.

The relationship between negative emotional expression and negative self-reported affect, with 95% confidence interval.

Table 1

Parent Characteristics (n = 69)

		Positive Self-Reported Affect			Negative Self-Reported Affect		
	***N* (%)**	**Mean**	**SD**	***P*-value**	**Mean**	**SD**	***P*-value**
Parent, Age							
21-34y	23 (33)	34.6	7.4	Ref	31.0	7.1	Ref
35-38y	20 (29)	36.0	8.4	0.55	27.4	12.2	0.29
39-66y	24 (35)	34.8	7.7	0.47	25.4	9.2	0.072
Unknown	2 (3)	34.5	16.3	--	34.0	4.2	--
Parent, Type							
Mom	41 (59)	34.9	7.6	Ref	29.1	9.8	Ref
Dad	25 (36)	35.8	7.9	0.73	27.8	9.5	0.87
Other[a]	3 (5)	29.3	9.0	--	21.0	1.7	--
Parent, Race							
White	49 (71)	34.9	7.4	Ref	27.8	9.5	Ref
Black	10 (15)	37.9	6.7	0.25	29.6	10.5	0.62
Other	5 (7)	27.2	7.5	--	36.7	4.5	--
Unknown	5 (7)	37.2	10.1	--	24.6	9.1	--
Parent, Relationship							
Married/partnered	49 (71)	34.3	7.5	0.39	28.6	9.3	0.50
Other	20 (29)	36.5	8.4		27.2	10.1	
Parent, Education							
High School	13 (19)	36.6	8.4	Ref	34.5	8.2	Ref
College	33 (48)	34.4	7.0	0.33	28.4	9.4	0.15
Graduate School	14 (20)	34.5	8.4	0.68	23.2	8.6	0.069
Unknown	9 (13)	35.3	9.6	--	26.6	9.1	0.30

Note: Values were not reported if cell sizes were 5 or less.

[a]Other includes one stepmother, one grandmother, and one aunt.

Table 2

Child Characteristics ($n = 47$)

		Positive Self-Reported Affect			Negative Self-Reported Affect		
	***N* (%)**	**Mean**	**SD**	***P*-value**	**Mean**	**SD**	***P*-value**
Child, Age							
Less than 1 year	11 (23)	33.9	8.6	Ref	31.7	6.4	Ref
1-4 years	14 (30)	34.7	7.8	0.78	29.7	10.5	0.52
5-9 years	11 (23)	34.3	8.1	0.76	24.3	8.5	0.019
10-17 years	9 (19)	37.2	6.7	0.26	24.5	10.9	0.057
18-24 years	2 (5)	40	1.4	--	38.5	4.9	--
Child, Gender							
Female	24 (51)	36.0	7.4	Ref	29.5	10.2	Ref
Male	23 (49)	33.8	8.1	0.28	27.0	8.8	0.33
Child, Insurance							
Private	18 (39)	34.9	7.7	Ref	27.4	8.4	Ref
Medicaid	23 (49)	35.8	8.2	0.66	28.3	10.8	0.80
Low cost/limited/none	3 (6)	33.0	2.9	--	32.5	8.8	--
Unknown	3 (6)	27.5	7.8		28.0	11.5	
Child, Complex Chronic Condition Category							
Neuromuscular	14 (30)	33.8	8.3	Ref	29.8	8.2	Ref
Metabolic	12 (26)	35.6	8.3	0.58	28.9	10.5	0.80
Malignancy	10 (21)	35.2	7.5	0.59	31.0	8.8	0.72
Congenital	7 (15)	36.1	6.2	0.49	24.9	9.5	0.18
Respiratory	2 (4)	38.3	6.5	--	15.7	2.3	--
Gastrointestinal	1 (2)	20	0	--	20	0	--
Cardiovascular	1 (2)	36.0	0	--			--

Note: Values were not reported if cell sizes were less than 5.

Table 3

Relationship Between Positive Emotional Expression and Self-Reported Positive Affect

	N	% Change	95% CI	*P*-value
Unadjusted Model				
Positive Emotional Expression	69	−7.4%	−13.0%, −1.8%	0.02
Adjusted Model				
Positive Emotional Expression	69	−7.0%	−14.6%, −0.5%	0.057
Parent Age Category, 21-34y		Ref		
Parent Age Category, 35-38y		8.2%	−11.4%, 27.7%	0.16
Parent Age Category, 39-66y		9.6%	−6.0%, 25.2%	0.20
Parent Race, White		Ref		
Parent Race, Black		2.9%	−15.8%, 21.5%	0.12
Parent Race, Other		−18.1	−46.0%, 9.8%	0.18
Parent Education, High School		Ref		
Parent Education, College		−3.5%	−24.9%, 17.9%	0.30
Parent Education, Graduate School		−6.6%	−34.4%, 21.2%	0.20
Child Insurance, Private		Ref		
Child Insurance, Medicaid		−2.3%	−17.3%, 12.7%	0.12
Child Insurance, Low Cost/Limited/None		5.0%	−16.7%, 26.6%	0.31
Illness Trajectory		−2.6%	−11.4%, 6.1%	0.28
Phone Interview, In Person		Ref		
Phone Interview, Phone		−2.8%	−17.6%, 12.0%	0.041

Note: Values were not reported if cell sizes were less than 5. Imputed results using *N*=69 are reported.

Table 4

Relationship between Negative Emotional Expression and Self-Reported Negative Affect

	N	% Change	95% CI	*P*-value
Unadjusted Model				
Negative Emotional Expression	69	6.0%	−2.8%, 15.0%	0.18
Adjusted Model				
Negative Emotional Expression	69	9.4%	0.6%, 18.3%	0.04
Parent Age Category, 21-34y		Ref		
Parent Age Category, 35-38y		−10.6%	−35.6%, 14.4%	0.24
Parent Age Category, 39-66y		−14.7%	−35.7%, 6.2%	0.20
Parent Race, White		Ref		
Parent Race, Black		−1.8%	−32.7%, 29.0%	0.90
Parent Race, Other		33.9%	−2.8%, 70.5%	0.42
Parent Education, High School		Ref		
Parent Education, College		−16.5%	−44.0%, 11.1%	0.28
Parent Education, Graduate School		−37.0%	−68.8%, −5.1%	0.28
Child Insurance, Private		Ref		
Child Insurance, Medicaid		−5.6%	−27.1%, 16.1%	0.15
Child Insurance, Low Cost/Limited/None		3.2%	−28.0%, 34.3%	0.28
Illness Trajectory		3.6%	−6.0%, 13.1%	0.12
Phone Interview, In Person		Ref		
Phone Interview, Phone		−21.8%	−49.6%, 6.1%	0.21

Note: Values were not reported if cell sizes were less than 5.

Imputed results using *N*=69 are reported.