

Original Article

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 in which parents typically experience strong emotions.

Objectives. To explore emotion using the Linguistic Inquiry and Word Count (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 semistructured interview about their children and experience with medical decision making. The transcribed interviews were analyzed with the 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 the illnesses of their children and the experience of medical decision making were more likely to report lower levels of positive affect on the PANAS: increase in the standard deviation of positive emotional expression was associated with an unadjusted 7.4% decrease in the self-reported positive affect ($P = 0.015$) and an adjusted 7.0% decrease in the self-reported positive affect ($P = 0.057$) after modeling for potential confounders. Increase in the standard deviation of negative emotional expression was associated with an adjusted 9.4% increase in the self-reported negative affect ($P = 0.036$).

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. *J Pain Symptom Manage* 2013;45:542–551. © 2013 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.

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Key Words*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 to understand their child's medical condition and can more effectively participate in the 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. 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 sad and angry regarding 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 the emotional experiences of parents 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 the 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 as positive or negative according to their affective valence, 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 undergoing treatment for substance abuse,¹³ women participating in online support groups for breast cancer,¹⁴ linguistic styles in children with attention deficit hyperactivity disorder¹⁵ and in other psychological research.¹⁶⁻¹⁸

When used 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. Although prior studies on 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 et al.²⁰ recommend the use of such measures of emotional expression as a supplement to self-report measures. Therefore, in this study, we explore emotion using the LIWC and a self-report questionnaire to better understand the relationship between these two measures of emotion in a pediatric care context.

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

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