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Parent-Child Interaction Style And Adjustment To Pediatric Cancer Treatment

Benjamin D. Goodlett
Wayne State University,

PARENT-CHILD INTERACTION STYLE AND ADJUSTMENT TO PEDIATRIC CANCER TREATMENT

by

BENJAMIN D. GOODLETT

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CHAPTER 1 PARENT-CHILD INTERACTION STYLE AND ADJUSTMENT TO PEDIATRIC CANCER TREATMENT

Introduction

Advances in medicine have resulted in drastic increases in the rate of survival for children with cancer. In the 1960s, the 5-year survival rate for children with cancer was only 28% (Ries, Harras, Edwards, & Blot, 1996). In contrast, more than 80% of children with cancer currently survive 5 years or more (American Cancer Society, 2013b). Parallel to increases in survivorship has been a focus on children's and their families' ability to adapt to treatment and long-term survivorship (for review see Patenaude & Kupst, 2005). In particular, increased emphasis has been placed on understanding children's distress during treatment (Kazak et al., 2012) and long-term psychosocial functioning (Wakefield et al., 2010). Many families navigate the uncertainty and stress of treatments successfully. The functioning of children and parents improves over time (Sawyer, Antoniou, Toogood, & Rice, 1997; Tsai et al., 2013); however, 25-30% of children experience long-term personal, family, or social difficulties (Patenaude & Kupst, 2005).

Families with children undergoing cancer treatment often experience high levels of uncertainty (De Graves & Aranda, 2008) and complex medical regimens, including chemotherapy, surgery, radiation therapy, and other types of treatment (American Cancer Society, 2013a). Hospitalization and many days in outpatient clinics are often necessary. Monitoring treatment response typically involves medical procedures such as blood draws, bone marrow aspirations, and lumbar punctures. Invasive treatment procedures are rated by parents and children as one of the most stressful aspects of cancer (American Cancer Society, 2013a). The identification and reduction of in-treatment distress has been identified as a key to improving the quality of life for pediatric cancer patients during treatment (Kazak et al., 2012),

and children's adjustment during treatment predicts their long-term psychosocial outcomes (Kazak et al., 1997; Stuber et al., 1997). Communication (verbal and non-verbal) between the parent and the child is an important predictor of the child's treatment-related distress and is likely to also predict their long-term adjustment (Blount et al., 1989; Cline et al., 2006; Peterson et al., 2007). Therefore, understanding how parents and children communicate with each other during treatment is important for helping families navigate the distress experienced during treatment sessions.

Several different research groups have looked at the impact of parent behaviors on their child's coping and distress during hospital visits. As an example, the Dyadic Prestressor Interaction Scale (DPIS) was developed to look at mother-child interactions before contact with a physician, across a variety of pediatric settings (Bush, Melamed, Sheras, & Greenbaum, 1986); however, children undergoing cancer treatment were not recruited for the study. The DPIS focuses on specific parenting behaviors (ignoring, reassurance, distraction, restraint, agitation, and information) and child attachment-related behaviors (attachment, distress, exploration, and prosocial). As another example, Blount and colleagues created a series of coding systems that focus on adult behaviors as predictors of child coping and distress behaviors: Child-Adult Medical Procedure Interaction Scale (CAMPIS; Blount et al., 1989; Blount, Sturges, & Powers, 1990), CAMPIS-Revised (Blount et al., 1997) and CAMPIS-Short Form (Blount, Bunke, Cohen, & Forbes, 2001). These studies added important information on how parent behavior can impact a child in the hospital room. Specific maternal verbalizations, such as non-procedural talk and humor, often precede coping behaviors from their child; while statements of reassurance, apologies, criticism, or that give control over the start of a medical procedure to the child often precede displays of distress from their child (Blount, Bunke, & Zaff, 2000).

Parent-Child Interactions: A Dyadic Perspective

Previous research on parent-child interactions during medical procedures have identified specific behaviors that contribute to distress or coping behaviors in children; however, the existing research has not fully examined the process by which parents and children interact. In addition to specific statements and behaviors of each individual during interactions, there is a dynamic relationship between the parent and child that fluctuates, and supports or negates, the needs of each member of the parent-child dyad. For several decades, developmental psychologists have advocated for understanding parent-child dynamics as a communal process in which the child is actively shaping his/her environment (Bell, 1968; Maccoby, 1992). With methodological advances, psychologists have begun to include a focus on the style of interactions, or how interactions unfold, for parents and children. From a dynamic systems perspective, the parent-child dyad is a system that is always changing and self-organizing (Hollenstein, 2011). Describing the organization of an interaction can provide valuable insights about families' responses to stressful circumstances. For example, do parents and children interact in a way that can lead to flexible adaption to changes in situations and demands? In addition to flexibility, parent-child interactions are marked by a give-and-take responsiveness (i.e., *mutuality*) which is important for child socialization and self-regulation (Kochanska, 1997; Kochanska, Gross, Lin, & Nichols, 2002). The proposed study will expand on the existing research on parent-child interactions within the context of pediatric cancer by focusing on the process of how parents and children navigate the stress of treatment sessions as a dyad.

Rigidity and flexibility have long been key terms used by theorists and researchers to describe dyadic systems (Hollenstein, 2011; Werner, 1946). Rigidity can be defined as the lack of response variability or the lack of adaptability of behavior (Werner, 1946). In the child

development literature, rigidity in parent-child interactions when the child is in kindergarten is associated with child externalizing behavior problems (Granic & Patterson, 2006). Dyadic flexibility includes the ability to work through negative emotional states while displaying a broad emotional range to return to a neutral or positive interaction (Hollenstein, Granic, Stoolmiller, & Snyder, 2004). The opposite of rigidity, flexibility, is marked by adaptive changes in parent and child behavior or emotions in response to environmental demands (Hollenstein et al., 2004). Flexibility is associated with decreased levels of externalizing problems (Lunkenheimer, Olson, Hollenstein, Sameroff, & Winter, 2011). Incorporating these notions of rigidity and flexibility into conceptualizations of responses to stressful child medical procedures may prove fruitful because the effect of specific parenting behaviors on child responses to treatments are not always intuitive. For example, experimental studies suggest that parental reassurance, generally a positive construct, increases displays of child distress (Manimala, Blount, & Cohen, 2000). Treatment sessions present a unique parenting challenge. Rigid use of parenting strategies, which may in other situations be positive, could result in negative outcomes (e.g., increased child distress). Parents need to be flexible in coping with the stress of the treatment room and determining which behaviors reduce the distress of the child.

Other conceptualizations of the parent-child dyad focus on "mutuality." Dyadic mutuality is used to describe parent-child interaction styles that are positive, responsive, and cooperative (Deater-Deckard & O'Connor, 2000). Dyads with a mutually responsive orientation are receptive and responsive to each other's overt and subtle cues (Kochanska, 2002). Shared positive affect and coordination in enjoyable routines are also important components of a mutually responsive orientation (Kochanska, 1997). Development of parent-child dyadic mutuality is child specific (Deater-Deckard & O'Connor, 2000). The same mother may interact with her two children with

different levels of mutuality. Mutuality has been examined as an important contributor to the development of conscience with low dyadic mutuality associated with increased risk for aggressive behavior and conduct problems (Kochanska, 1997, 2002); moreover, mutuality is also foundational to the development of parent-child coregulation behaviors and child self-regulation (Kochanska, 1997; Maccoby, 1992). Higher levels of dyadic mutuality are associated with lower parent-rated child behavioral and emotional problems (Deater-Deckard & O'Connor, 2000). Dyadic synchrony, a similar concept, is associated with better adjustment at kindergarten entry and easier integration into playing with peers (Harrist, Pettit, Dodge, & Bates, 1994; Vizziello, Ferrero, & Musicco, 2000).

Child Characteristics That May Shape Dyadic Interactions

Models describing the process of parent-child interactions can benefit from accounting for the role of individual characteristics of the child. This perspective recognizes that children are active participants in their families, and parent behavior is responsive to differences in patterns of child behavior (Bell, 1968; Kiff, Lengua, & Zalewski, 2011). Temperament refers to child characteristics that are "constitutionally based individual differences in reactivity and self-regulation, influenced over time by heredity, maturation, and experience" (p. 55, Rothbart, Ahadi, Hershey, & Fisher, 2001). For children undergoing cancer treatment, high effortful control and ego-resilience are two temperament/personality characteristics that are associated with parents' response to child distress during treatments and the child's health-related quality of life (Harper et al., 2014; Harper, Penner, Peterson, Albrecht, & Taub, 2012).

Effortful control was introduced by Rothbart and colleagues as a label for the aspects of temperament that include the ability to willfully focus and shift attention, inhibit or initiate behaviors, to plan, and to detect errors (Rothbart, 1989). Effortful control is associated with the

development of a conscience and morals (Kochanska, Barry, Jimenez, Hollatz, & Woodard, 2009), and effortful control is important for understanding how children and infants modulate their emotions and behavior (Eisenberg et al., 2004; Kochanska, Murray, & Harlan, 2000). Ego-resiliency is a personality component that includes flexibility, sturdiness, and the ability to 'bounce back' from stressful situations (Block & Block, 1980). Children who are high in ego-resilience can adapt to stressful situations, adapt coping behaviors, and attempt new problem-solving strategies (Eisenberg et al., 2003).

From a transactional effects perspective, parents and children simultaneously influence each other (Sameroff & Mackenzie, 2003). A robust literature links parental behavior to children's temperament (for review see Kiff et al., 2011). High levels of intrusive parenting, in particular, have been demonstrated to predict lower levels of effortful control and ego-resilience in children (Kochanska et al., 2009; Taylor, Eisenberg, Spinrad, & Widaman, 2013). Although less research is available, child temperament characteristics also predict their mother's well-being and parenting style (Laukkanen, Ojansuu, Tolvanen, Alatupa, & Aunola, 2013). There are a number of mechanisms through which child temperament may be related to the interaction style of a parent-child dyad in a hospital room. Based on variations in temperament, children may receive differential treatment, react differently to the treatment room, fit better or more poorly with the demands of the situation, or employ different coping strategies (Wachs, 2006). Previous research in an adolescent sample demonstrated the importance of effortful control and ego-resilience in the development of positive social skills (Hofer, Eisenberg, & Reiser, 2010), and effortful control and ego-resilience are robust predictors of health-related quality of life and distress during procedures for pediatric cancer patients (Harper et al., 2014; Trentacosta et al., 2016). Effortful control and ego-resilience likely play an important role in allowing children to

engage in adaptive co-regulation processes with their parents, which are displayed as flexible and mutual interaction styles.

Child Response to Treatment Procedures

Predicting child pain and distress is a major focus of child oncology research (Kazak et al., 2012), and parent behavior is clearly linked to children's responses to treatment procedures (Blount et al., 1989; Dahlquist, Power, & Carlson, 1995; Dahlquist et al., 2001; Penner et al., 2008). While previous research has focused on the role of specific parenting behaviors on predicting child distress, the style in which parents and children interact likely impacts the child's response to the treatment session. For parents and children, the topic of conversations (e.g., positive or conflict) and recent stressful experiences for the child are associated with the flexibility of emotion displays during interactions for mother-daughter dyads (Hollenstein & Lewis, 2006). Evidence for links between interpersonal flexibility and emotion states is also found in marital interactions. Distressed couples display a tendency towards mutually negative emotion states and have difficulty shifting away from those emotion states (Gottman & Levenson, 1986; Gottman & Notarius, 2000). These studies of marital and mother-daughter relationships indicate that interpersonal flexibility is related to the experience of negative emotions, and these findings join a rich history examining associations between emotions and an individual's interpersonal behavior (Forgas, 2002; Paulhus & Martin, 1988). Similar research has not yet been conducted within the context of parent-child dyads navigating pediatric cancer. The proposed study will explore associations between parent-child interaction style (i.e., dyadic flexibility and mutuality) leading up to a cancer treatment procedure with the child's response (i.e., distress and cooperation) during the procedure.

Assessment of child pain and distress can be difficult due to children's limited vocabulary and reading level. Several methods of assessing child pain or distress have been developed including having the child point to a line marked 0 to 100, coloring a pain thermometer, or having children point to one of several pain faces (Tomlinson, von Baeyer, Stinson, & Sung, 2010). Faces pain scales are popular because they are easy to administer, do not require numerical literacy, and can be used with young children (Tomlinson, von Baeyer, Stinson, & Sung, 2010). Faces pain scales correlate with other self-report indices of pain (von Baeyer, 2006) and with ratings by parents (Chambers, Giesbrecht, Craig, Bennett, & Huntsman, 1999).

Child Adjustment: Externalizing and Internalizing Behavior Problems

Children undergoing treatment for cancer may experience decreases in their health-related quality of life (Kazak et al., 2012; Wakefield et al., 2010). In addition, children who are hospitalized with acute and chronic illnesses are at more risk than healthy controls for both externalizing and internalizing problems (Levy, Kronenberger, & Carter, 2008). Behavioral problems for children have a long history of being grouped into externalizing (e.g., aggression, hyperactivity, delinquent) and internalizing (e.g., anxiety, depression, social withdrawal) problems (Achenbach, 1978; Achenbach & Edelbrock, 1979). Typically, externalizing behaviors decrease with age for children, while internalizing behaviors increase for girls with age (Leve, Kim, & Pears, 2005). For children diagnosed with cancer, they may be at elevated risk for internalizing problems at the time of diagnosis and as much as two years post diagnosis (Sawyer et al., 1997).

Parenting influences change in both externalizing and internalizing problems (Galambos, Barker, & Almeida, 2003). Previous studies of parent-child interactions found links between

flexibility and externalizing problems and internalizing problems (Hollenstein et al., 2004; Lunkenheimer et al., 2011). From a dynamic systems perspective, parent-child flexibility and mutuality are linked to both internalizing and externalizing because social interactions are viewed as the engine from which long-term, macro-level development emerges. Granic and Patterson (2006) provide an extensive model for the processes through which daily, moment-to-moment interactions build long-term relationships and long-term child development. The social processes from which externalizing behaviors emerge include *coercive cycles* with caregivers (Patterson, Littman, & Bricker, 1967) with parents and *deviancy training* with peers (Dishion, Spracklen, Andrews, & Patterson, 1996). Through repeated interactions, children learn that aversive and aggressive behaviors can result in outcomes they desire. Dynamic systems research on flexibility has primarily focused on externalizing problems. Dyadic flexibility is linked to child internalizing problems; however, the evidence is less consistent (Hollenstein et al., 2004).

Dyadic mutuality has also been linked to externalizing problems and emotional problems (Atzaba- Poria, Pike, & Deater- Deckard, 2004; Deater-Deckard, Atzaba-Poria, & Pike, 2004). Dyadic mutuality is evident from early infancy and is believed to play a key role in the internalization of parent values and morals (Kochanska & Murray, 2000). Children who participate in a highly mutual dyad develop a willing and cooperative attitude toward their socialization that has been proposed to be a key link to the development of conduct problems (Kochanska, Kim, Boldt, & Yoon, 2013). Similar to dyadic flexibility, considerably less research on dyadic mutuality has focused on mechanisms of protection from developing internalizing problems. However, dyadic mutuality is thought to contribute to a child's internal regulation as well as their ability to rely on their parent for co-regulation of emotions (Grusec & Davidov, 2010).

Pediatric cancer is a unique context to examine parent-child interactions that have not previously been included in dynamic systems models or studies of dyadic flexibility and mutuality. Children and their parents face challenges with symptoms, appointments, procedures, and uncertainty that requires adaptation. From a dynamic systems perspective, periods of significant change and uncertainty are referred to as *phase transitions*. Phase transitions pose a unique challenge and opportunity to families to discover and establish new patterns of behavior and interaction. Developmental psychologists have incorporated dynamic systems models to examine parent-child relationships as toddlers learn to walk and as they begin to be fed solid food (Thelen, Ulrich, & Wolff, 1991; van Dijk, Bruinsma, & Hauser, 2016). In adolescents, dynamic systems studies have helped to explain dramatic changes in social relationships with peers and families (Granic, Hollenstein, Dishion, & Patterson, 2003; Smetana, Campione-Barr, & Metzger, 2006). This study looks at parent-child relationship during pediatric cancer treatment with the goal of adding to our conceptual and practical understanding of how children and their families can adapt and thrive.

Specific Aims

Specific Aim 1. To examine dyadic flexibility and mutuality as parent-child interaction styles during a pediatric cancer treatment session. ***Hypothesis 1a,b*:** Inter-rater agreement for dyadic flexibility (H1a) and mutuality (H1b) will be adequate. ***Hypothesis 1c,d:*** Latent factor scores representing flexibility (H1c) and mutuality (H1d) will be identified. ***Hypothesis 1e:*** Dyadic flexibility and mutuality will be positively associated; higher flexibility will be associated with higher mutuality.

Specific Aim 2. To investigate child temperament characteristics (i.e., effortful control and ego-resilience) as predictors of parent-child dyadic flexibility and mutuality during a hospital

visit. ***Hypotheses 2a-d***: High levels of effortful control and ego-resilience will predict higher levels of flexibility (H2a,b), and mutuality (H2c,d) in parent-child interactions. The regression of dyadic mutuality and flexibility on child temperament will be examined in the context of relevant covariates.

Specific Aim 3. To examine parent-child dyadic flexibility and mutuality as predictors of children's distress and cooperation during pediatric cancer treatment sessions. ***Hypotheses 3a-d***: Interactions that are flexible and mutual will be associated with lower child distress (3a,b) and higher child cooperation (3c,d). Further, dyadic flexibility and mutuality will predict lower child distress and higher cooperation in the context of relevant covariates.

Specific Aim 4. To examine whether dyadic flexibility and mutuality are related to longer-term internalizing and externalizing behavior problems in children. ***Hypotheses 4a-d:*** Higher levels of flexibility and mutuality will be associated with lower levels of externalizing (H4a,b) and internalizing (H4c,d) behavior problems at both 3-month and 9-month longitudinal follow-up assessments. Dyadic flexibility and mutuality will also be examined as predictors of child externalizing and internalizing problems in the context of relevant covariates.

CHAPTER 2 METHODS

Participants

Participants were recruited as part of a larger longitudinal study at two major children's hospitals in the United States. Participants were children (ages 3-12 years), who had recently been diagnosed with cancer, and their primary caregiver (henceforth referred to as 'parents'). Families were excluded from participation if the parent was unable to read or speak English, the child had been diagnosed with cancer for more than 18 months, or if the child was not receiving any of the procedures that would be video-recorded. The larger longitudinal study includes 143 children, and the current study focuses on a subsample of 83 children who had at least 5-minutes of video-taped interaction with their parent prior to a port start procedure. Demographic information for the current study is presented in Table 1. In the two months before study entry, the children had undergone a mean of 3.51 lumbar punctures (*SD*=2.77, range=0-12), 1.49 bone marrow aspirations (*SD*=1.62, range=0-6), and 11.11 port start procedures (*SD*=8.88, range=0-30). The majority of children were diagnosed with acute lymphoblastic leukemia (ALL; 68.7%), followed by Wilm's tumors (8.4%), and non-Hodgkin's lymphoma (4.8%). The remaining participants (18% of subsample) had a diagnosis that occurred in less than 3% of the sample.

Study Overview

Study recruitment and data collection occurred at two children's hospitals: one in the Midwestern United States and one in the Southeastern United States. The study was reviewed and approved by the institutional review board at each institution. The aim of the parent study was to provide a basis for interventions designed to reduce the negative psychosocial consequences of pediatric cancer by investigating the origins of these problems. Participants were approached for recruitment by the medical staff at each institution. For interested families,

written informed consent was obtained from the participants' parents at study entry by research staff, and verbal assent was obtained from children. Data were collected at three phases. A flow-chart of data collection is presented in Figure 1 *1) Baseline assessment:* primary caregivers ("parents") completed questionnaires about themselves and their children including demographic and child temperament data. 2) *Treatment assessments:* at time points 2, 3, and 4 parents completed questionnaires immediately before and after up to three of their children's procedures (i.e., port start, bone marrow aspiration, or lumbar punctures). Video-tapes were recorded in the procedure room before and during the procedures while the child was awake. The current study uses port start procedures which involves inserting a needle into a port implanted in the child's chest. 3) *Follow-up assessment*: time-points 5 and 6 were completed approximately three and nine months after the last study treatment assessment. Parents completed questionnaires about themselves and their children. Parents received $15 gift cards for the baseline assessment and each video-recorded procedure. Parents received $20 gift cards for the 3- and 6-month follow-ups. Children received $10 gift cards for the baseline and each video-recorded procedure. For the parent study, 89% of families approached by research staff agreed to participate.

Video-Tape Coding and Global Ratings Procedures

Data collection during treatment sessions included video-taping of the family from the time they entered the hospital room until the end of the child's medical procedure. Families had up to three video-taped hospital room procedures (see Figure 1 for study timeline). For families with more than one video-taped port start procedure, the visit used for the current project was randomly selected. The video-tapes were separated into the preprocedure and procedure phases. The preprocedure phase begins when the family enters the hospital room, and the procedure phase begins when the nurse who is going to perform the procedure enters the room to perform

the procedure. For the families included in the current study, the average time spent in the hospital room was 1 hour 29 minutes with an average of 57 minutes spent in the preprocedure phase. Coding and ratings were completed by undergraduate students. The students assisted in piloting the coding and rating system for four months.

The video-taped treatment sessions were coded using a modified version of the Specific Affect (SPAFF) coding system (Atzaba-Poria et al., 2004; Coan & Gottman, 2007). The SPAFF system was originally designed to track changes in emotional state in real time (i.e., continuously) for romantically involved couples engaged in conversation. Emotion codes were based on a combination of facial expression, gestures, posture, voice tone and volume, and speech rate. SPAFF includes 18 mutually exclusive codes: affection, enthusiasm, humor, interest, validation, neutral, anger, belligerence, contempt, criticism, defensiveness, disgust, domineering, fear/tension, sadness, stonewalling, threats, and whining. Over the course of multiple studies, Hollenstein and colleagues modified the SPAFF to a collapsed set of codes that could be more reliably implemented with parent-child dyads (e.g., Hollenstein & Lewis, 2006; Lunkenheimer et al., 2011). The SPAFF codes were collapsed into positive, neutral, and negative categories with negative codes split by their social function – active social engagement versus withdrawn or disengaged types of behaviors (Coan & Gottman, 2007). The modified SPAFF system focuses on Positive Engagement (Interest, Validation, Affection, Humor, and Enthusiasm), Neutral Engagement, Negative Engagement (Criticism, Domineering, Contempt, Belligerence, and Threats) and Negative Disengagement (Sadness, Fear/Tension, Defensiveness, Whining, and Stonewalling). Coding was completed using Studiocode 5 [Computer Program].

Following SPAFF coding, the research observer immediately completed a modified version of the Parent-Child Interaction System (PARCHISY; Deater-Deckard, Pylas, & Petrill,

1997). The original PARCHISY is an 18-item rating scale with 7-point Likert-type items (1=none, 7=constantly). The PARCHISY includes ratings of parent and child positive affect, negative affect, and responsiveness to the other member of the dyad. Ratings were also completed for the dyad's level of reciprocity and conflict. The PARCHISY scale for the proposed study was a modified version of the original coding system with items not directly related to the proposed study's goals removed. During piloting, the original anchors of the Likert-type items resulted in responses that were restricted in range – none of the families were constantly engaged, which placed a ceiling on the possible range of scores. New anchors based on both duration and intensity were established.

Two raters were trained on both the SPAFF and PARCHISY systems. The current project focused only on port start procedures because the local anesthesia, as opposed to general anesthesia, allowed the child to be alert and interact with the parent, and provided a rating of distress during the procedure. For piloting and training with the coding system, a combination of port start and other procedures (e.g., intra-muscular injection) were used. For the procedures during which children were sedated, only the preprocedure phase was used for training. An initial set of 14 video-tape segments were coded as a group by the two raters and myself. The continuous SPAFF coding was completed as a group, with each person taking turns as the official coder. The PARCHISY ratings were then rated independently by each person, and the ratings were immediately discussed. An additional 22 video-tape segments were then identified to be coded independently and discussed as a group. All of the practice video-tapes were double-coded by the two raters, and weekly meetings were held to discuss discrepancies, refine the coding manual, and create a shared mental model of the coding system.

Raters viewed each interaction two times. The continuous coding for the parent and the child were completed in separate passes. The order of participant video-tapes was randomized. The order of the coding passes, child-first or parent-first, was also randomized. Coders were allowed to pause and rewind as much as they needed prior to recording the code. The PARCHISY ratings were completed after both of the passes for the SPAFF coding. Double-coding was completed for one in three videos. To minimize coder drift, weekly discussions were held so that all double-coded videos were discussed. A consensus was reached on all coding and ratings. For double-coded video-tapes, random selection was used to identify the set of codes and ratings to be used in analyses.

Measures

Effortful control. Child effortful control was rated by the parent using age-appropriate temperament scales developed by Rothbart and colleagues (Putnam, Ellis, & Rothbart, 2001; Rothbart, 2006; Rothbart, Ahadi, Hershey, & Fisher, 2001). Given that the demonstration of effortful control changes with age, Rothbart and colleagues developed different questionnaires adjusted for different age groups. The Child Behavior Questionnaire (ages 3-6) (Rothbart et al., 2001) and the Temperament in Middle Childhood Questionnaire Version 3 (ages 7-9) (Simonds & Rothbart, 2004) include subscales that measure Attention Control, Inhibitory Control, Low Intensity Pleasure, and Perceptual Sensitivity. For children ages 10-12 the Early Adolescent Temperament Questionnaire (Ellis & Rothbart, 1999) includes Attention Control, Activation Control, and Inhibitory Control subscales. For each age group, effortful control is defined as the average of the average score on the subscales for each age-group's questionnaire. Each subscale contains 5-10 items with a 5-point scale (1= “almost always untrue of your child” to 5= “almost always true of your child”). Effortful control ratings for each of the three questionnaires were

standardized to create a single age-standardized distribution. The overall coefficient alphas (α) were .87 (ages 3-6), .86 (ages 7-9), and .80 (ages 10-12).

Ego-resilience. Parents completed an adapted version of Block and Block's (1980) Q-sort (Eisenberg et al., 2003). The scale is designed to tap into children's flexible, adaptable behavior. Example items include "Can bounce back or recover after a stressful or bad experience" and "Freezes up when things are stressful, or else keeps doing the same thing over and over again (reverse scored)". The scale includes 11 items that were rated using the same 5-point Likert scale used with effortful control items. The coefficient alpha was .72 (ages 3-6), .82 (ages 7-9), and .72 (ages 10-12).

Parent-child dyadic flexibility. The video-taped interactions during the preprocedure and procedure phases of the hospital visit were coded using a modified version of the SPAFF (Coan & Gottman, 2007). As noted in the video-tape coding and ratings procedure section, the SPAFF is a holistic coding system that takes verbal statements, non-verbal behaviors, and tone of voice to identify displays of emotion. The SPAFF has been adapted for a number of dynamic systems studies with parents and children (e.g., Hollenstein et al., 2004; Lunkenheimer et al., 2011). For the current study, dyadic flexibility refers to the moment-to-moment changes in affect within a given context. This conceptualization fits with a larger model of flexibility, the Flex3 Model, that includes context-to-context changes and long-term adjustment to environmental changes (Hollenstein, 2015).

Dyadic flexibility was estimated using the SPAFF coding from the video-taped interactions using state space grids (SSGs) in Gridware (Lamey, Hollenstein, Lewis, & Granic, 2004). SSGs were constructed with each member of the dyad on each axis (i.e., caregiver on the *y*-axis and child on the *x*-axis). A hypothetical SSG is presented in Figure 1. In the hypothetical

grid, the dyad starts with parent and child in the neutral valence. The size of the circle in each square represents the amount of time spent in that grid. Each arrow represents a transition to a new dyadic state. In the example, the first transition occurs when the parent displays a positive emotion. A wide range of individual cell and whole-grid measures were generated that provide information on various aspects of the SSG. For the current study, three measures were used as indices of flexibility: (1) *Transitions* was a count of the number of movements between cells on the grid. Frequent changes of dyadic states were represented by a higher value on this measure. Transitions were the only indicator of flexibility found to be significantly correlated with the duration of the video-tapes, $r(66)= .32$, $p<.01$. Therefore, the indicator transitions represents transitions per second to account for variation in video-tape lengths. (2) *Average mean duration* is calculated by dividing the total duration in the cell by the number of different times the dyad occupied that cell. The average across cells gives the average mean duration value. Low average mean durations, or less time spent in a single cell, indicate more flexible behavior. (3) *Dispersion* is the spread of behavior across cells, adjusted for the total number of cells in the grid, and inverted so that values range from 0 (no dispersion: all behavior in one cell) to 1 (maximum dispersion: behavior equally distributed across the grid). The formula for calculating dispersion is

$$1 - \frac{(n\Sigma(d_i/D)^2) - 1}{n - 1}$$

In the formula, the sum of the squared proportional durations across all cells were corrected for the number of cells and inverted. D is the total duration, d_i is the duration in cell i, and n is the total number of cells (Hollenstein, 2013).

Parent-child mutuality. Ratings from the PARCHISY system were used to create a latent construct to represent mutuality. Deater-Deckard and colleagues define mutuality as parent

and child responsiveness to each other (contingent, immediate), cooperation (planning, agreement on how to proceed), and reciprocity (matching affect, eye contact, "turn-taking" in verbal and nonverbal interaction) (Deater-Deckard, Atzaba-Poria, & Pike, 2004; Deater-Deckard & O'Connor, 2000; Deater- Deckard, 2000). Their definition is based on the work of Kochanska and colleagues (Kochanska, 1997); however, Kochanska defines a mutually responsive orientation as being comprised of responsiveness and shared positive affect (Kochanska, 2002). The key distinction between the two conceptualizations is whether positive affect vs. shared affect is a component of mutuality. For the current study, mutuality was operationally defined as the composite of parent and child responsiveness and dyadic reciprocity.

Child pain/distress and cooperation. The Wong-Baker Faces scale was used to assess children's pain and distress (Wong & Baker, 1988). The scale uses six points with a drawing of a human face. The ratings range from 1 = "no distress" to 6 = "extreme distress." Pain/distress ratings were provided by the child, the parent, and a nurse. Three research staff provided additional independent ratings after reviewing the recording from the video-taped treatment session. Child cooperation was rated on a 7-item Likert-type scale with 1= "totally uncooperative" to 7= "totally cooperative." Ratings of child cooperativeness were provided by the child's parent, medical staff, and independent ratings by research staff. Children did not provide ratings of their cooperativeness. Distress and cooperation measures for the present analyses were from the single port-access procedure used for the flexibility coding and mutuality rating.

Child internalizing & externalizing behavior problems. Parents completed the Child Behavior Checklist (CBCL; Achenbach & Rescorla, 2000) at baseline, 3-month follow-up, and 9-month follow-up. The CBCL is a broad-band measure of child behavioral problems. Parents

provide ratings of 0= "Not True of Child," 1= "Somewhat/Sometimes True," and 2= "Very/Often True." The Externalizing and Internalizing Problems scales were composites of several subscales. The Externalizing Problems scale includes items related to hyperactivity, aggressive behavior, and delinquency. Examples of items include "argues a lot," "gets into everything," "gets in many fights." The Internalizing Problems scale includes items measuring depression/anxiety and social withdrawal. Examples of internalizing items include "cries a lot," "feelings are easily hurt," and "gets upset when separated from parents".

Multiple forms of the CBCL were available for different sources of information (e.g., teachers versus parents). Additionally, a preschool version is available for children ages 1.5-5 years, and a school-age version is available for children ages 6-18 years. In the parent study, children 6 years-old were given the preschool (1.5-5 years) version of the CBCL. Cronbach's alpha was used to evaluate the internal consistency of the CBCL Internalizing and Externalizing problems for each time-point (baseline, 3-month follow-up, and 9-month follow-up). The coefficient alphas ranged from .75 to .95 with most values greater than .80.

Covariates. Several child and family demographic variables were considered as potential covariates: parent education, household income, child age, child gender, the number of port start in the two months prior to study entry, and time in treatment at study entry. Parent ratings of child internalizing problems and externalizing problems at baseline were also considered. The potential covariates were selected based on previous research that suggests they may be associated with psychosocial outcomes (Klassen, Anthony, Khan, Sung, & Klaassen, 2011; Patenaude & Kupst, 2005; Tsai et al., 2013). For each of the study aims, bivariate correlations were run for each of the potential covariates and the predicted variable within the aim.

Covariates that were significantly correlated with study variables were included as part of the subsequent analyses.

CHAPTER 3 ANALYTIC PLAN

Values for missing data were imputed using substitution of the sample mean. The scales used to operationalize effortful control, ego-resilience, externalizing problems, and internalizing problems have different questions and subscales depending on the age group of a participant. Equivalent scores were created by creating *z*-scores to standardize within each age group. A single distribution was then created by averaging the *z*-scores. For each aim, potential covariates were examined using bivariate correlations with the primary study variables. Only covariates that were associated with the hypothesized outcome for each aim were included within that set of analyses.

A**im 1.** The first goal of the current project was to demonstrate the adaptation of observational coding and rating systems that were typically used with video-recordings from home or laboratory settings for use with video-recordings of a treatment procedure within a hospital setting. Dyadic flexibility and mutuality were summarized using descriptive statistics, and bivariate correlations were used to describe the data generated from the observational coding, including observer ratings, ratings of child distress and cooperation, and parent ratings of child temperament and externalizing/internalizing behavior problems. (H1a) Inter-rater agreement for the real-time coding used to create the dyadic flexibility construct was established through percent-agreement of the coding data as well as bivariate correlations of the SSG measures for double-coded videos. (H1b) Krippendorf's α was used to assess inter-rater agreement on coding dyadic mutuality (Krippendorff, 2004). Krippendorff's α provides a flexible evaluation of inter-rater agreement that allows raters to be interchangeable, and it provides a consistent metric across different levels of data (e.g., ordinal or interval) (Hayes & Krippendorff, 2007).

Dyadic flexibility was examined by plotting the data from the collapsed SPAFF codes on State Space Grids (SSGs). SSGs are a method to analyze two synchronized time series of categorical or ordinal variables (Lewis, 2004; Lewis, Lamey, & Douglas, 1999). SSGs are used to represent a dynamic system with a set number of possible states that encompass all possible states that exist within the system. The system's state is defined by the position of the two variables that constitute the system. Although an infinite number of states are theoretically possible, systems tend to return to a smaller set of states referred to as attractor states (Granic & Hollenstein, 2003). SSG analyses have been successfully applied to several studies in which the number of categories used were five or fewer (Granic et al., 2003; Granic & Lamey, 2002; Hollenstein et al., 2004). An example of a SSG is presented in Figure 2. The factor structure of dyadic flexibility and dyadic mutuality during hospital visits for port-access procedures in pediatric cancer treatment were examined through factor analysis. (H1c) A latent factor of dyadic flexibility was predicted to be able to be created using three measures obtained from SSGs: the number of dyadic emotion states displayed (cell range), the frequency of transitions between emotion states (transitions), and the overall spread of displays across the possible emotional states (dispersion). (H1d) A latent factor of dyadic mutuality was predicted to be comprised of ratings of parent responsiveness, child responsiveness, and dyadic reciprocity as indicators.

Aim 2. Effortful control and ego-resilience were examined as predictors of parent-child interaction style during a video-taped hospital room procedure. Effortful control and ego-resilience were hypothesized to predict (H2a) dyadic flexibility and (H2b) dyadic mutuality. These associations were examined using bivariate correlations. As exploratory analyses, the subscales of effortful control were each examined as predictors of dyadic flexibility and dyadic mutuality. The associations between effortful control and ego-resilience with dyadic flexibility

and dyadic mutuality were further tested while accounting for a range of covariates. Effortful control and ego-resilience were hypothesized to predict (H2a) dyadic flexibility and (H2b) dyadic mutuality while controlling for relevant covariates identified from significant bivariate correlations with effortful control and ego-resilience. Hierarchical regressions predicting dyadic flexibility and mutuality were conducted with the covariates entered in the first step and child temperament (effortful control and ego-resilience) entered in the second step.

Aim 3. Dyadic interactions that were flexible and mutual were hypothesized to be associated with lower child distress (H3a,b) and higher child cooperation (H3c,d). The associations with dyadic flexibility and dyadic mutuality were examined using bivariate correlations. These associations were further tested while accounting for potential covariates. Dyadic mutuality and dyadic flexibility were hypothesized to predict (H3a,b) child distress and (H3c,d) child cooperation while controlling for covariates that were associated with child distress and cooperation. Hierarchical regressions were used with covariates entered in the first step and dyadic mutuality and flexibility entered into the second step in separate analyses predicting distress and cooperation.

Aim 4. Higher levels of dyadic flexibility and mutuality were hypothesized to predict lower levels of externalizing (H4a,b) and internalizing (H4c,d) behavior problems. Hierarchical linear regression equations were used to test the association between each of the dyadic interaction style constructs and the behavior problems at time point 5 (3-month follow-up) and time point 6 (9-month follow-up). Basic demographic variables such as child age, gender, and treatment location were considered for inclusion as control variables. Potential covariates were included if they were significantly correlated with any of the follow-up ratings of child internalizing or child externalizing problems.

CHAPTER 4 RESULTS

Missingness

Missingness was evaluated at the scale level for the primary study variables. There were a total 996 possible data points with 8.9% missing scale data. Scales for effortful control and ego-resilience had minimal missing data. For effortful control, only 5 data points were missing at the subscale level (1.5% of data points). For ego-resilience, 5 observations were missing at the item level (0.5% of data points). Using mean substitution, no data were missing for effortful control or ego-resilience at the scale level.

For child distress and cooperation, missing data were minimal. For the aggregated distress and cooperation variables, no data were missing. For the individual reports of child distress (e.g., parent report, nurse report) 17 data points were missing, which was 5% of the distress ratings. For child cooperation, 10 data points were missing, which was 4% of the cooperation ratings.

Missing data for the dyadic observational data were primarily the result of limitations of the length of the available videotapes. For the preprocedure phase, four videos that were long enough to be coded (at least 5 minutes of preprocedure) had procedure phases that were not long enough to be coded. Similarly, four videos had procedure phases that could be coded, but the preprocedure phase was not long enough to be coded. Additionally, three of the preprocedure videotapes had sufficiently long durations, but the data from the videos were not included in analyses because one or more members of the dyad were out of the room for a large portion of the time. More specifically, preprocedure videos were dropped from analyses if both members of the dyad were present in the room for less than 100 seconds.

At the 3-month follow-up, data were available for 72 participants (87% of the original sample) for internalizing problems and for 73 participants (88% of the original sample) for externalizing problems. At the 9-month follow-up, data were available for 64 participants (77% of the original sample) for internalizing problems and 62 participants (74% of the original sample) for externalizing problems.

Descriptive Statistics & Data Reduction

Dyadic Flexibility. Examples of the SSGs for the preprocedure and procedure phases of the video observations are presented in Figure . For each member of the dyad, there were four emotion states coded: Negative Engagement, Negative Disengagement, Neutral, and Positive. Time spent outside of the room is also represented in the grid so that each grid is 5 x 5. Only time spent in the room was coded for emotional valence, and interactions with one or both members of the dyad outside of the room were treated as missing for all analyses. The size of shaded circles indicates the duration of each individual visit, and the lines between cells represent transitions.

Descriptive statistics for dyadic emotional valence during the preprocedure phase of the hospital visit are provided in Table 2. The table includes the average time (seconds) spent in each cell, average number of transitions to each cell, and the percentage of dyads who visited the cell at least one time. The neutral-neutral cell had the longest average amount of time with dyads spending, on average, more than 5 minutes in that state. A large portion of the dyads (33%) had at least one member exit the room during the preprocedure phase. The mutually positive dyadic state was visited by 70% of families with an average duration of 33 seconds across the preprocedure phase. Conversely, 10% of dyads had at least one visit to the mutual negative engagement cell. This dyadic state includes mutual frustration, anger, or hostility.

The procedure phase descriptive statistics for dyadic emotional valence are presented in Table 3. Similar to the preprocedure phase, dyadic neutral-neutral was the most common state with greater than 98% of dyads having at least one occurrence of that state. The parent positive-child neutral cell was commonly visited with 89% of families visiting at least once, and the average duration in the cell was 80.85 seconds (*SD* = 99.19). Parent-neutral and child-negative disengagement were also common with 78.5% of dyads visiting the cell, and the average duration in the cell was 86.14 seconds (*SD* = 106.31).

Dyadic Mutuality. Descriptive statistics for the ratings of parent responsiveness, child responsiveness, and dyadic reciprocity for the preprocedure and procedure phases of the hospital video tapes are presented in Table 4. T-tests were conducted to determine if there were significant changes in ratings between the two phases of the videotapes. Parents were more responsive during the procedure phase than they were during the preprocedure phase. Child responsiveness and dyadic reciprocity did not significantly differ between the two phases of the hospital visit.

Child Temperament. Descriptive statistics for child temperament (i.e., effortful control and ego-resilience) are presented in Table 5. Mean, median, and range are provided for each age group separately as well as combined. Consistent with prior work (Harper et al., 2012), the study was not able to enroll enough children to separate children by age groups and conduct meaningful analyses with sufficient power. The authors of the temperament questionnaires were consulted on strategies for combining effortful control scores (S. Putnam, personal communication, July 15, 2013). A single age-standardized distribution of effortful control scores was created. The same process was used for ego-resilience scores. The age-standardized

distributions from the parent study were used, which resulted in means that were not 0.0 and the standard deviation for ego-resilience was not 1.00.

Distress and cooperation. Child distress and cooperation descriptive statistics are presented in Table 6. Examination of histograms for child distress and cooperation revealed that child distress appeared to be bimodal, with peaks of data at the positive and negative ends of the distribution. Child cooperation was significantly negatively skewed with the median value close to the maximum range of possible scores. For child cooperation, data transformations were implemented; however, the severity of the skew could not be normalized. Therefore, data transformations were not utilized for any subsequent analyses. In the results section Aim 3: Child Distress and Cooperation, the use of a median split to account for the data distribution is described.

An exploratory factor analysis with Promax rotation conducted for the ratings of child cooperation provided by the parent, medical staff, and a research observer revealed a single factor solution that accounted for 81% of the variance in the indicators. The indicator loadings were .77 for parent rating, .83 for medical staff rating, and .85 for research observer rating. Only one factor was extracted. The exploratory factor analysis with Promax rotation conducted for ratings of child distress provided by parents, medical staff, research observer, and the child also revealed a single factor solution. The latent factor of child distress accounted for 77% of the variance in the indicators. The factor loadings were .87 for parent rating, .74 for medical rating, .94 for child rating, and .77 for research observer rating. For subsequent analyses, indicators were combined by using a mean average for the ratings of child distress and the ratings of child cooperation.

Child internalizing & externalizing behavior problems. Descriptive statistics for child internalizing and externalizing problems are presented in Table 7. Similar to the child temperament scales, child internalizing and externalizing reports are collected with scales that varied by the child's age. Similar to effortful control and ego-resilience scores, a single age-standardized distribution was created. Descriptive statistics for internalizing and externalizing are presented separated by age group as well as the combined age-standardized scores.

Covariates

Bivariate correlations between potential covariates and the study variables are presented in Table 8. Variables were considered appropriate covariates for individual analyses if they were significantly correlated with one or more possible dependent variables. Parent education, household income, and child age were associated with dyadic flexibility or dyadic mutuality during the hospital visit, and they were used as covariates for analyses of child temperament as a predictor of dyadic observational data. Child age and treatment location were used as covariates when examining dyadic observational data as a predictor of child distress and cooperation. Child internalizing and externalizing problems, at the 3-month and 9-month follow-up, were associated with a number of possible covariates: household income, treatment site, baseline internalizing problems, and baseline externalizing problems.

Aim 1: Dyadic Flexibility and Mutuality

Dyadic flexibility. Inter-rater reliability for dyadic flexibility was assessed through two methods (Hypothesis 1a): percent agreement and correlations between SSG measures. First, percent agreement was calculated for the amount of time (seconds) that both coders assigned the same emotional valence to each member of the dyad. For the preprocedure phase, double-coded data were available for 14 videos, and data were available for 22 double-coded procedure videos.

An unequal amount of video-tapes with at least 5 minutes of interaction were available for the preprocedure and procedure phase of the hospital visit. In addition, 3 of the double-coded videos for the preprocedure phase had video tapes that were > 5 minutes (minimum to be included in the study), but both members of the dyad were in the room together for less than 100 seconds. These videos were dropped due to lack of relevant data.

The percent agreement in the preprocedure phase was 75% for the child codes and 76% for the parent codes. The percent agreement for the procedure phase was 82% for the child codes and 69% for the parent codes. Inter-rater reliability was also assessed by calculating the correlation between the two coders for the variables generated from SSGs created from the emotion valence coding. The correlation coefficients were .61 for cell range, .76 for events per second, and .59 for cell dispersion.

I hypothesized (Hypothesis 1c) that the variability indicators generated from SSGs could be combined to create latent factors of dyadic flexibility for the videotaped hospital sessions. A factor analysis using maximum likelihood estimation and Promax rotation was used to explore the latent factors of dyadic flexibility during the preprocedure and procedure phases using transitions, range, and duration of each phase of the hospital visit as indicators. A two-factor solution with factor 1 being the preprocedure phase and factor 2 being the procedure phase was supported. A two-factor solution accounted for 71% of the observed variance. The loadings for the preprocedure factor were .72 for range, .74 for dispersion, and .94 for transitions per second. The loadings for the procedure factor were .76 for range, .62 for dispersion, and .76 for transitions per second. The cross-factor loadings were less than or equal to .43.

Next, transitions, range, and dispersion for the preprocedure, then the procedure phase, were combined for subsequent analyses using principle components analysis (PCA). PCA was

used for the combination of variables because each variable was set to a different scale, and PCA is supported as an appropriate method of data reduction. For the preprocedure phase, a PCA indicated a single component solution accounted for 77% of the variance. The single component, dyadic flexibility, had factor loadings of .86 for cell range, .86 for dispersion, and .91 for transitions per second. A PCA was also conducted for the procedure phase of the hospital visit. A single component solution accounted for 64% of the variance. The component loadings were .86 for cell range, .69 for dispersion, and .84 for transitions per second. Descriptive statistics for dyadic flexibility during the preprocedure and the procedure phases of the hospital visit, along with each indicator, are presented in Table 9.

Dyadic mutuality. Inter-rater reliability for dyadic mutuality was assessed with Krippendorf's alpha (Hypothesis 1b). For the preprocedure phase (n =14 double-coded), Krippendorf's alpha was .57 for parent responsiveness, .73 for child responsiveness, and .67 for dyadic reciprocity. For the procedure phase (n = 22 double-coded), Krippendorf's alpha was .82 for parent responsiveness, .69 child responsiveness, and .67 for dyadic reciprocity. There is not a definitive required minimum level for Krippendorf's alpha when establishing inter-rater agreement; however, alpha $\geq$ .667 has been recommended for scholarly arguments (Krippendorff, 2004).

Consistent with the observational data for dyadic flexibility, a factor analysis using maximum likelihood estimation and Promax rotation was used to determine if a linear combination of parent responsiveness, child responsiveness, and dyadic reciprocity could be represented by a latent factor of *dyadic mutuality* (Hypothesis 1d). A two-factor solution was supported with the preprocedure phase indicators loading primarily on factor 1 and the procedure phase indicators loading primarily on factor 2. A two-factor solution accounted for 70% of the

observed variance. The loadings for dyadic mutuality during the preprocedure phase were .78 for parent responsiveness, .81 for child responsiveness, and .80 for dyadic reciprocity; the loadings for dyadic mutuality during the procedure phase were .57 for parent responsiveness, .98 for child responsiveness, and .70 for dyadic reciprocity. The cross-factor loadings were less than or equal to .35. Based on the support for the factor structure, preprocedure mutuality and procedure mutuality were each calculated for subsequent analyses as the mean of the three components. A mean aggregation was selected over a PCA because the ratings were all on the same scale, and interpretation of the raw scores is facilitated by a mean average.

Dyadic flexibility and mutuality were hypothesized to be positively correlated (Hypothesis 1e). All four of the dyadic observational measures were positively correlated with each other (Table 10). The correlation coefficients ranged from .28 to .62 (all *p*s < .05).

Aim 2: Child Effortful Control and Ego-resilience

I hypothesized that effortful control and ego-resilience would predict dyadic flexibility and mutuality such that higher levels of effortful control and ego-resilience would be associated with higher levels of dyadic flexibility and mutuality (Hypotheses 2 a through d). However, effortful control was not significantly correlated with the observational measures of dyadic flexibility or mutuality. Ego-resilience significantly correlated with dyadic flexibility during the procedure phase, such that higher ego-resilience was associated with higher dyadic flexibility (Table 10).

Potential associations between child temperament, dyadic mutuality, and dyadic flexibility were further evaluated using hierarchical regressions. Parent education, household income, and child age were included as covariates. The hierarchical regressions are presented in Table 11. Ego-resilience remained a significant predictor of dyadic flexibility during the

procedure phase while controlling for parent education, household income, and child age. Effortful control and ego-resilience did not predict dyadic flexibility (preprocedure) and mutuality (preprocedure and procedure) in the other regressions.

As a set of exploratory analyses, the individual subscales that contribute to the effortful control construct were examined for bivariate associations with the observational dyadic variables (i.e., mutuality, flexibility). The bivariate correlations separated by the three age groups: 3-6 years, 7-9 years, and 10-12 years are presented in Table 12. Additionally, two of the subscales, attentional focusing and inhibitory control, were included for each of the age groups. Similar to the overall effortful control measure, scores across the groups were aggregated for these two scales by creating z-scores within each age group, and a mean of the two distributions of z-scores was computed.

For the dyads with 3-6 year-old children, several subscales were positively associated with dyadic mutuality or dyadic flexibility during the procedure phase. Dyadic flexibility during the preprocedure phase was not significantly correlated with any of the effortful control subscales. No other statistically significant correlations were found among subscales and dyadic flexibility or dyadic mutuality.

Aim 3: Child Distress and Cooperation

I hypothesized that dyadic flexibility and mutuality would each be associated with lower levels of child distress (Hypotheses 3 a and b) and higher levels of child cooperation (Hypotheses 3 c and d). Child distress and cooperation were strongly correlated with each other such that higher levels of child distress were associated with lower levels of cooperation, $r = -.78$, $p < .01$. The correlations with dyadic flexibility and dyadic mutuality were not significant

(Table 10). The largest (although, non-significant) correlation was observed between child distress and dyadic flexibility during the procedure phase, $r = .22$, $p > .05$.

Of the potential covariates examined in Table 8, child age and treatment location were found to have a significant correlation with either child distress or cooperation. Hierarchical linear regressions were conducted to examine the associations between the dyadic observational data and child distress and cooperation while controlling for child age and treatment location (Table 13). The regression equation with child age and treatment location as covariates in step one and the four dyadic observational measures in step two predicated a significant amount of variation in child distress, R^2=.36, p<.01. The dyadic observational measures entered in step two did not add a signification amount of variance explained in child distress over that accounted for by child age and treatment location. The findings for the regression predicting child cooperation were similar. The overall regression accounted for a significant amount of variance in child cooperation, R^2=.30, p<.01. Child age and treatment location were significant predictors of child cooperation. In the second step of the regression, dyadic mutuality during the procedure phase was a significant predictor of child cooperation; however, the four dyadic observational measures did not account for a significant amount of additional variance in child cooperation.

During the creation of descriptive statistics, child distress and cooperation were observed in histograms to have non-normal distributions. Child distress appeared bimodal, and child cooperation appeared skewed with the majority of children rated at the high end of the scale. As noted earlier, data transformations did not appear to improve the distribution of child cooperation. As an exploratory step, a median split was used to dichotomize child distress and cooperation. Logistic regressions were then run with child age and treatment site as covariates and flexibility and mutuality in the preprocedure and procedure phases as predictors. Consistent

with the linear regressions, child age was a significant predictor of child distress and cooperation, but the dyadic observational data did not have a significant association with child distress or cooperation.

Aim 4: Child Externalizing and Internalizing Problems

I hypothesized that dyadic mutuality and flexibility during hospital visits would be associated with lower parent ratings of child internalizing and externalizing behavior problems at the 3- and 9-month follow-up time points (Hypotheses 4 a through d). Bivariate correlations between the dyadic observational measures and the parent report of child behavior problems are presented in Table 10. Dyadic mutuality and dyadic flexibility were not significantly associated with child internalizing or externalizing problems at the initial (3-month) follow-up. Mutuality and flexibility during the procedure phase were both negatively correlated with the 9-month follow-up ratings of child externalizing problems such that higher levels of mutuality and higher levels of flexibility were associated with lower ratings of child externalizing problems.

From the table of potential covariates and study variables (Table 8), household income, treatment site, baseline internalizing problems, and baseline externalizing problems were significantly associated with externalizing or internalizing problems in at least one of the follow-ups. Regressions were conducted with dyadic mutuality during the preprocedure and procedure phases as well as dyadic flexibility during the preprocedure and procedure phases predicting child internalizing and externalizing behavior problems at 3-month and 9-month follow-up assessments (Table 14). In each of the four regressions, the baseline measure of problems, internalizing or externalizing, significantly predicted the same variable collected at 3-month and 9-month follow-up. In addition, dyadic flexibility during the procedure phase was a significant predictor of fewer externalizing problems at the 9-month follow-up while accounting for several

covariates, including the baseline measure of externalizing problems. Dyadic flexibility did not significantly predict externalizing problems at the 3-month follow while controlling for household income, treatment site, baseline internalizing problems, and baseline externalizing problems. Using the same covariates, dyadic mutuality did not significantly predict internalizing or externalizing problems at the 3-month or 9-month follow-ups.

CHAPTER 5 DISCUSSION

Increased survival rates for children with cancer are one of medicine's modern marvels. With increased survival, there has been a parallel increase in examining the quality of life for children who undergo and survive cancer treatment. Most children can adapt; however, treatment remains stressful and a portion of children experience serious decreases in social and emotional functioning (Patenaude & Kupst, 2005). The diagnosis and treatment of cancer remains difficult for families. The uncertainty of life and what to expect creates significant stress for families. Additionally, the treatment itself is often rated as more anxiety provoking than the disease (Hedström, Haglund, Skolin, & Von Essen, 2003). Thankfully, psycho-oncology is an emerging, interdisciplinary field of study and practice with a focus on lifestyle and oncology (see Holland, 2002 for a historical review). Transition to survivorship is now an important part of children's care, and the long-term effects of cancer and treatment are being studied. Research on the risk of cancer treatment helps us to understand some of the long-term negative consequences, such as post-traumatic stress, and research on the resilience of children and their families has provided evidence that some families are stronger and more resilient after going through the treatment process (Barakat, Alderfer, & Kazak, 2006).

The purpose of this project was to add to our understanding of individual differences in children's responses to cancer treatment. The study of child characteristics includes temperament traits, which are the emerging characteristics of children that form their personality. Understanding child temperament is important for understanding treatment-related quality of life (Harper et al., 2014) and distress during hospital visits among pediatric cancer patients (Trentacosta et al., 2016). Understanding parental responses to their child's treatment is also important. Parents' verbal and nonverbal behaviors impact child distress (Cline et al., 2006;

Peterson et al., 2007), and parents also experience distress, which impacts their behaviors within the hospital room (Penner et al., 2008).

Dynamic systems theory is relevant to dyadic parent and child responses to treatment-related stress. This theory is based on concepts of multiple layers of relationships and events that affect each other both in the moment and across time. Dynamic systems theory has been used to examine how early parent-child and child-peer relationships establish social patterns in children that can lead to externalizing problems and juvenile delinquency (Granic & Patterson, 2006). Dynamic systems theory has also been used to understand how real-time interactions between mothers and daughters influence the risk of developing depression (van der Giessen et al., 2015). Dynamic systems theory is also relevant to families' adaptation to cancer treatment because the cancer diagnosis and treatment procedures contribute to great upheaval. During these times of change, new behavioral patterns emerge, and existing behavioral patterns often change. The malleable nature of these periods can present a risk to the child if maladaptive behaviors are learned or if too much stress results in trauma.

Aim 1: Dyadic Flexibility and Mutuality

One of the major goals of this project was to utilize observational measures (i.e., dyadic flexibility and dyadic mutuality) that have been used to understand child development in other settings to understand parent-child interactions in a pediatric cancer treatment context. The SPAFF was created for marital couples (Coan & Gottman, 2007), but it was subsequently adapted for use with children at risk for externalizing behavior problems (Lunkenheimer et al., 2011). Similarly, the PARCHISY system is relevant to a wide range of parenting contexts, but it has primarily been used to examine gene by environment interactions in children with a focus on externalizing problems (e.g., Deater-Deckard & Petrill, 2004). Adapting these coding systems

provides an important contribution to the literature on child development and pediatric psychology by expanding the application of dyadic mutuality and flexibility to include parent-child dynamics during a medical treatment procedure. Historically, observational studies of child development have not included a focus on adverse health conditions, and pediatric studies have used primarily observational systems designed specifically for hospital settings, not general observational systems from the developmental literature.

The data properties (i.e., inter-rater agreement and factor structure) of the two systems support a successful adaptation. The inter-rater agreement was adequate. The availability of appropriate methods for assessing inter-rater agreement for continuous observational data is limited. Percent-agreement between the child emotion valence and parent valence codes were calculated, and correlations across coders for the SSGs measures were used as a second method of examining inter-rater agreement. Strong correlations between the SSG measures between each of the two coders were found. The Krippendorf's α for the dyadic mutuality measures were generally above the recommended level of .667 (Krippendorff, 2004).

The creation of latent factors for dyadic flexibility and dyadic mutuality was supported by factor analyses. For dyadic flexibility, a two-factor solution, one for the preprocedure phase and one for the procedure phase, was supported. For dyadic mutuality, a two-factor solution with the latent factors corresponding to the phase of the hospital visit was also found. The factor structure of dyadic mutuality and dyadic flexibility are consistent with the hypotheses that parent-child interaction dynamics can be identified in hospital rooms in a manner that is similar to other settings relevant to child development. In addition, the pattern of statistically significant correlations supports the construct validity of the two measures of parent-child interaction dynamics. Dyadic mutuality and dyadic flexibility are positively correlated with each other;

dyadic flexibility during the procedure phase was positively correlated with ego-resilience; and both dyadic flexibility and dyadic mutuality were negatively correlated with follow-up ratings of child externalizing problems. Based on the network of correlations, dyadic mutuality and dyadic flexibility, particularly during the procedure phase of treatment, appear to measure an adaptive parent-child interaction dynamic.

Aim 2: Child Effortful Control and Ego-resilience

Limited evidence is available for the role of child temperament in adapting to cancer treatment and survivorship. Child effortful control and ego-resilience were hypothesized to be important predictors of the parent-child dyad's behavior during hospital visits, which would be reflected in observed dyadic mutuality and flexibility. The hypothesis was partially supported. Higher ego-resilience was associated with higher dyadic mutuality, but not dyadic flexibility, during the procedure phase. Our previous research with a subsample of the same parent study found an association between ego-resilience and child health-related quality of life (Harper et al., 2014). Additionally, evidence supports a correlation between ego-resilience and lower treatment-related anxiety (Trentacosta et al., 2016). The findings from this study highlight ego-resilience as an important child characteristic for understanding children's responses to cancer treatment. More specifically, a child's capacity to "bounce back" from stressful experiences seems to play a role in the parent-child dyad's ability to flexibly respond to a cancer treatment procedure.

Effortful control was not significantly associated with dyadic mutuality or flexibility. This finding is consistent with previous research in a non-cancer sample of children where effortful control was correlated with child internalizing and externalizing problems but not observations of dyadic flexibility (Lunkenheime, Albrecht, & Kemp, 2013). One possible explanation for the discrepancy is that effortful control and ego-resilience are theorized to be

important for two different types of emotion regulation. More specifically, effortful control is linked to voluntary regulation, and ego-resilience has connections to involuntary/reactive regulation (Eisenberg et al., 2003). Most of the research on effortful control has focused on studies of children who are at risk for impulsivity and externalizing problems (e.g., Eisenberg et al., 2010), and the role of effortful control and emotion modulation has mostly focused on anger (e.g., Kochanska, Murray, & Harlan, 2000). Effortful control, as an overall ability of willful behavioral control, may be less directly relevant to populations not at risk for impulsivity problems and regulation of anger.

An alternative explanation could be that effortful control contributes to the development of other child characteristics that are more directly related to the child's behavior and adjustment to cancer treatment. For example, effortful control is important to the development of ego-resilience (Taylor, Eisenberg, Spinrad, & Widaman, 2013), and an indirect association from effortful control through ego-resilience to child quality of life while undergoing cancer treatment was previously supported in a subsample of the same parent study (Harper et al.,2014). This hypothesis is supported by Miller and colleagues who found that effortful control is associated with child anxiety and depression in the context of pediatric cancer, but they did not find a direct association between effortful control and child cancer-related distress or hospital room coping (Miller et al., 2009).

Aim 3: Child Distress and Cooperation

I hypothesized that higher levels of dyadic flexibility and dyadic mutuality would be associated with lower levels of child distress and higher levels of child cooperation. No statistically significant associations were found. One possible methodological explanation could be the distribution of the data for distress and cooperation. Distress appeared to be bi-modal in its

distribution with peaks on both the high and low ends of distress. In contrast, cooperation was highly skewed with most children rated at the high end of cooperation. Data transformations and a median split with logistic regression did not alter the pattern of non-significant associations.

The creation of factor scores of child distress and child cooperation is supported by exploratory factor analyses. In each of the factor analyses, the indicators for child distress and child cooperation had loadings greater than .75. The constructs were created by combining the perspectives of multiple raters (e.g., for distress ratings were provided by the child, parent, a medical staff member, and a research assistant). The strong factor structure for both child distress and cooperation provides support that the theorized constructs are being assessed. However, the overall lack of significant correlations with other study variables is perplexing.

Conceptually, flexible or mutual dyads may sometimes include children who experience heightened distress but adaptively use coping skills. Therefore, situations where a child expresses distress should not be uniformly characterized as a negative social process because high distress could represent either dysregulation within the parent-child dyad or an adaptive activation of the parent-child coregulation system (Granic, O'Hara, Pepler, & Lewis, 2007). From this perspective, specific subgroups of parent-child dyads may exhibit distinct patterns of associations between child distress during hospital visits and measures of dyadic functioning. The inclusion of relevant parent or child characteristics as moderators is needed to more completely understand how child distress and cooperation in the hospital room are related to parent-child dyadic functioning. A small sample, and resultant low power, precluded looking at moderation in this study.

Aim 4: Child Externalizing and Internalizing Problems

The final goal of this study was to examine how parents and children interact within hospital rooms is related to important child psychosocial outcomes including internalizing problems and externalizing problems. Within the general child development literature, parent-child dyads who have higher rates of flexibility and mutuality create households that foster positive child growth and limit the impact of risk factors (e.g., maternal depression). This study extends those findings by demonstrating that parent-child interactions in the hospital room are associated with longer-term maladjustment, especially child externalizing problems. More specifically, dyads who displayed more emotional flexibility during the procedure phase of a port-access procedure included children who were rated as having fewer externalizing problems at the 9-month follow-up. Within pediatric psycho-oncology, screening and early detection of psychosocial problems have been a major focus for standards of psychosocial care of children (Wiener, Kazak, Noll, Patenaude, & Kupst, 2015). Although not the focus of this study, there was an impressive association between demographic and screening data at study entry and child psychosocial outcomes. However, approximately half of the variance in children's subsequent behavior problems was not explained by these baseline and demographic variables. The role of in hospital interactions will likely prove to be invaluable to further our understanding of how children adapt throughout cancer treatment and into survivorship.

Limitations and Strengths

A number of limitations are worth noting. Recruitment of participants is understandably difficult for pediatric cancer patients. This results in a number of practical and statistical limitations. Subgroup analyses based on treatment or demographic characteristics are problematic due to concerns of sufficient power. Similarly, analytic techniques are also limited

due to issues of power. For example, mediation and moderation analyses are underpowered with the current sample size. Children who are undergoing cancer treatment have several unique characteristics that could impact the current study. Cancer treatment, particularly for brain tumors, may result in a negative effect on neurocognitive and psychosocial functioning. Brain tumor survivors are at increased risk for social maladjustment (Schulte & Barrera, 2010). Those deficits worsen with time, which is believed to be related to disease chronicity, but limited information is available on the effects of family factors on social outcomes. Accompanying any neurological changes is the potential for an impact on child temperament. Among children with brain tumors, there is some evidence that effortful control may be adversely affected by cancer treatment (Salley et al., 2015).

A difficult to assess limitation of observational systems is the degree to which uncommon behaviors are adequately sampled. For survey data, a rating of zero is often considered to represent the absence of a construct, but for observational data zero may indicate that an insufficient window of time was used to capture the behavior (Stoolmiller, Eddy, & Reid, 2000). This study included two windows of coding (i.e., preprocedure and procedure), but the validity of Negative Engagement from the SPAFF is difficult to assess due to the low rate of occurrence across these two windows. Additionally, this study's observational coding approach did not differentiate the intensity of emotions within each valence. This precludes the ability to examine the strength of emotions as a predictor of child outcomes. Finally, the study used the same observational coding system to assess parent and child emotions (a modified version of the SPAFF). Future research might benefit from more specific adaptations or modifications for children to better capture unique aspects of emotion expression among children relative to adults."

The use of multimodal data collection including observational measures is a strength of this study. The risk of correlation due to a single reporter and a single method of data collection (surveys) is prevented through the use of multiple reporters for child distress and cooperation as well as the use of observational methodology to capture parent-child interaction dynamics. Additionally, the data are longitudinal, which prevents problems associated with cross-sectional data.

Conclusions

This study provides evidence for dyadic flexibility during a medical procedure as a potentially important marker of child and family adaptation to cancer treatment. Dyadic flexibility during the procedure phase was associated with higher levels of child ego-resilience, a temperament trait linked to better adaptation to cancer treatment (Harper et al., 2014). Additionally, dyadic flexibility predicted externalizing problems at a 9-month follow-up while controlling for several important covariates including baseline externalizing problems.

This study has several practical implications for children and families navigating pediatric cancer treatment. This study builds on a growing literature that focuses on parent-child interactions as a dyadic and dynamic process. Previously, the literature has focused primarily on families that are "at-risk" due to risk factors for externalizing problems or maternal depression. This study provides an example of how studies of child development can be incorporated into a new setting with a different type of "at-risk" population.

Recently, a set of standards for psychosocial care for children with cancer and their families was published (Wiener, et al., 2015). Included in the standards is a recommendation for procedural preparation and support (Flowers & Birnie, 2015). Flowers and Birnie explain that the benefits of procedural preparation and support are clearly demonstrated, but limited evidence

is available for which interventions work based on child characteristics, including temperament. This project highlights ego-resilience as a child characteristic that is related to flexible parent-child interactions during procedures, and our prior work has linked ego-resilience to children's longer-term quality of life (Harper et al., 2014).

The recommended standards of care for children undergoing cancer treatment include psychosocial therapies (Steele, Mullins, Mullins, & Muriel, 2015). A longstanding problem for the development of psychotherapy has been a barrier to understanding how therapy works (Kazdin, 2007). Dynamic systems theory, especially for parent-child interactions, posits that moment-by-moment interactions are a mechanism for socialization and long-term child adjustment or psychopathology (Granic and Patterson, 2006). The ability of fine-grained studies of parent-child interactions is supported by experimental data carried out in clinical and school settings. During a community-based parent-management intervention, children who had reductions in externalizing behavior were part of dyads that increased emotional flexibility during problem-solving tasks with their parents (Granic, O' Hara, Pepler, & Lewis, 2007). The Family Check-Up (FCU) is a system focused intervention that has been evaluated in multiple studies of families with at-risk children and adolescents (Dishion, Nelson, & Kavanagh, 2003; Dishion et al., 2008). Observational data of parent-child dyads provided evidence that families who benefited from the intervention had increased flexibility in the form of more positive engagement, rather than less negative engagement (Sitnick et al., 2015). A number of types of psychotherapy (e.g., Cognitive Behavioral, problem solving skills training, and medical family therapy) have been developed for children coping with cancer (Kazak et al., 2015), and the current study provides support for observations of family interactions for dyadic support as a method for evaluating the impact of interventions on in-hospital room behavior.

Table 1

Parent and Child Demographics Variables (N=83)

	Parent	Child
Mean age (*SD*)	34.25 (6.96)	6.43 (3.08)
Gender		
Male	87%	61%
Female	13%	39%
Race/ethnicity		
White	72%	71%
African American	21%	22%
Biracial	--	4%
Hispanic/Latino	4%	2%
Other	1%	1%
Household income		
<$20,000	34%	
$20,000-$59,000	29%	
$60,000-$100,000	28%	
>$100,000	10%	
Employment status		
Unemployed	51%	
Part-time	17%	
Full-time	31%	
Education		
Less than high school diploma	11%	
High school diploma	18%	
Some college	48%	
College degree or higher	23%	

Table 2

State Space Grid Descriptive Statistics by Cell for the Preprocedure Phase

Parent		Child				
		Neg engage	Neg diseng	Neutral	Positive	Out of room
Out of room	Time (*SD*)	0.07 (0.50)	0.06 (0.49)	13.44 (47.40)	2.77 (12.89)	9.43 (23.60)
	Transitions	0.03(0.17)	0.02 (0.12)	0.54 (1.43)	0.15 (0.67)	0.28 (0.56)
	Percent >0 Visit	2.9%	1.5%	20.6%	7.4%	22.1%
Positive	Time (*SD*)	0.77 (3.09)	15.50 (47.85)	75.38 (91.12)	33.25 (54.79)	0.40 (1.51)
	Transitions	0.21 (0.46)	1.03 (1.71)	5.99 (4.48)	2.38 (2.59)	0.16 (0.54)
	Percent >0 Visit	14.7%	42.6%	91.2%	70.6%	8.8%
Neutral	Time (*SD*)	1.91 (4.20)	20.50 (45.49)	329.10 (147.69)	31.77 (53.25)	14.96 (34.96)
	Transitions	0.52 (0.97)	1.91 (3.45)	9.93 (4.81)	3.53 (3.27)	0.59 (0.92)
	Percent >0 Visit	29.4%	55.9%	100.0%	73.5%	35.3%
Neg diseng	Time (*SD*)	0.00 (0.00)	0.00 (0.00)	0.77 (4.40)	0.25 (2.06)	0.00 (0.00)
	Transitions	0.00 (0.00)	0.00 (0.00)	0.10 (0.49)	0.03 (0.24)	0.00 (0.00)
	Percent >0 Visit	0.0%	0.0%	4.4%	1.5%	0.0%
Neg engage	Time (*SD*)	0.69 (3.35)	0.74 (3.55)	3.97 (8.22)	0.60 (2.95)	0.00 (0.00)
	Transitions	0.12 (0.35)	0.16 (0.63)	0.75 (1.52)	0.13 (0.45)	0.00 (0.00)
	Percent >0 Visit	10.3%	8.8%	35.3%	8.8%	0.0%

Note. Duration is presented in seconds. Neg engage = negative engagement, Neg disengage = negative disengagement.

Table 3

State Space Grid Descriptive Statistics by Cell for the Procedure Phase

		Child				
Parent		Neg engage	Neg disengage	Neutral	Positive	Out of room
Out of room	Duration (*SD*)	0.05 (0.49)	2.28 (15.73)	8.20 (49.45)	0.23 (1.36)	2.05 (15.41)
	Transitions	0.01 (0.12)	0.06 (0.31)	0.15 (0.44)	0.04 (0.17)	0.08 (0.29)
	Percent >0 Visit	1.3%	5.1%	10.1%	3.8%	7.6%
Positive	Duration (*SD*)	0.85 (2.48)	41.17 (67.92)	80.85 (99.19)	17.80 (34.24)	0.04 (0.36)
	Transitions	0.27 (0.61)	2.86 (3.01)	6.62 (4.95)	2.01 (2.18)	0.01 (0.12)
	Percent >0 Visit	16.5%	67.1%	88.6%	65.8%	1.3%
Neutral	Duration (*SD*)	2.28 (6.29)	86.14 (106.31)	292.95 (165.01)	27.86 (38.77)	0.39 (3.11)
	Transitions	0.61 (1.20)	4.73 (4.60)	10.58 (5.96)	3.48 (3.53)	0.10 (0.37)
	Percent >0 Visit	32.9%	78.5%	98.7%	65.8%	2.5%
Neg diseng	Duration (*SD*)	0.28 (2.67)	0.11 (0.69)	0.38 (2.17)	0.00 (0.00)	0.00 (0.00)
	Transitions	0.01 (0.12)	0.05 (0.24)	0.09 (0.43)	0.01 (0.12)	0.00 (0.00)
	Percent >0 Visit	1.3%	3.8%	5.1%	0.0%	0.0%
Neg engage	Duration (*SD*)	0.24 (1.10)	2.53 (7.26)	1.96 (6.86)	0.38 (2.05)	0.00 (0.00)
	Transitions	0.09 (0.35)	0.38 (1.04)	0.29 (0.76)	0.05 (0.17)	0.00 (0.00)
	Percent >0 Visit	6.3%	17.7%	17.7%	5.1%	0.0%

Note. Duration is presented in seconds. Neg engage = negative engagement, Neg disengage = negative disengagement.

Table 4

Descriptive Statistics for the PARCHISY Indicators of Dyadic Mutuality

		M	*SD*	Median	*r*	*t(df)*
Parent response	Preprocedure	4.92	1.91	5.00	.38**	-2.49 (74)*
	Procedure	5.53	1.94	7.00		
Child response	Preprocedure	4.09	1.68	4.00	.51**	1.11 (74)
	Procedure	3.78	1.65	4.00		
Dyad reciprocity	Preprocedure	4.37	1.97	5.00	.41**	0.31 (74)
	Procedure	4.24	2.13	4.00		
Dyad mutuality	Preprocedure	4.46	1.68	4.67	.52**	-0.57 (74)
	Procedure	4.52	1.62	4.67		

Response = responsiveness. Range for all variables is 1 to 7.

*$p<.05$

Table 5

Descriptive Statistics for Child Temperament

		N	*M (SD)*	Median	Range
Effortful control	3-6 years	47	24.69 (3.53)	24.75	16.25 to 32.50
	7-9 years	18	29.77 (3.68)	30.00	22.00 to 35.61
	10-12 years	18	21.11 (3.09)	21.33	16.00 to 27.33
	Combined	83	0.08 (1.0)	0.13	-2.52 to 2.45
Ego-resilience	3-6 years	47	43.43 (5.76)	44.00	32.00 to 55.00
	7-9 years	18	41.76 (6.74)	43.50	28.00 to 50.00
	10-12 years	18	42.24 (5.57)	42.00	32.00 to 54.00
	Combined	83	0.4 (1.05)	0.15	-2.36 to 2.20

Note: Combined = Linear combination of all three age groups after standardizing within age group.

Table 6

Descriptive Statistics for Child Distress and Cooperation During the Hospital Visit

	N	*M (SD)*	Median	Range
Distress parent rate	78	3.23 (1.87)	3.00	1 to 6
Distress medical rate	79	2.78 (1.58)	2.00	1 to 6
Distress observer rate	83	3.22 (2.02)	2.50	1 to 6
Distress child rate	75	2.95 (2.07)	2.00	1 to 6
Distress aggregate	83	3.05 (1.67)	2.58	1 to 6
Cooperation parent rate	78	5.64 (1.89)	7.00	1 to 7
Cooperation medical rate	78	5.73 (1.86)	7.00	1 to 7
Cooperation observer rate	83	5.60 (1.89)	6.67	1 to 7
Cooperation aggregate	83	5.69 (1.67)	6.33	1 to 7

Table 7

Descriptive Statistics for Parent Rating of Child Internalizing and Externalizing Problems

Variable	Age Group	N	*M (SD)*	Median	Range
Internalize T5	3-5 years at baseline	41	7.68 (5.65)	5.00	2 to 24
	6-12 years at baseline	34	7.03 (6.55)	5.50	0 to 23
	Combined	72	-0.19 (0.95)	-0.54	-1.23 to 2.90
Externalize T5	3-5 years at baseline	41	9.49 (6.88)	9.00	0 to 29
	6-12 years at baseline	34	5.85 (5.08)	5.00	0 to 21
	Combined	73	-0.10 (0.98)	-0.24	-1.50 to 2.87
Internalize T6	3-5 years at baseline	36	6.47 (4.85)	5.00	0 to 19
	6-12 years at baseline	33	7.06 (8.11)	5.00	0 to 31
	Combined	64	-0.09 (0.95)	-0.37	-1.40 to 2.59
Externalize T6	3-5 years at baseline	36	10.00 (7.54)	8.00	0 to 24
	6-12 years at baseline	33	6.91 (8.11)	4.00	0 to 32
	Combined	62	-0.08 (0.96)	-0.36	-1.43 to 2.29

Note: T5 = 3-month follow-up, T6 = 9-month follow-up. Combined = Linear combination of all three age groups after standardizing within age group.

Table 8

Bivariate Correlations Between Potential Covariates and Study Variables

	EC	ER	Mutual pre	Mutual proc	Flexible pre	Flexible Proc
Parent education	.21	.06	.12	.33**	-.05	.21
Household income	.12	.05	.09	.23*	-.10	-.01
Child age	.08	-.09	-.15	-.19	-.26*	-.07
Child gender	.24*	.10	-.07	.12	-.02	.07
Site	-.10	-.15	-.02	-.06	.02	-.17
2 month port start	-.06	-.01	-.15	-.01	-.10	.08
Time in treatment	-.01	.09	-.11	-.10	.06	-.10
Internalizing T1	-.14	-.51**	.12	.13	.16	-.01
Externalizing T1	-.48**	-.39**	.02	-.14	.27	-.12
	Distress	Cooperate	Internal T5	Internal T6	External T5	External T6
Parent education	.11	-.04	-.01	-.13	.13	-.21
Household income	.11	-.03	-.05	-.23	-.01	-.28*
Child age	-.52**	.39**	.01	.08	-.12	-.09
Child gender	.20	-.02	-.02	-.24	-.12	-.10
Site	-.13	.26*	.10	.26*	.18	.25
2 month port start	-.05	.01	.03	.22	.11	.15
Time in treatment	-.09	.09	.13	.10	.07	.04
Internalize T1	-.09	.15	.73**	.76**	.47**	.36*
Externalize T1	-.04	-.08	.35*	.55**	.63**	.60**

Note. 2 month port start denotes the number of port start procedures that occurred in the two months leading up to the baseline assessment. EC = effortful control. ER = ego-resiliene. Pre = preprocedure phase.. Proc = procedure phase. T1 = baseline assessment. T5 = 3-month follow-up. T6 = 9-month follow-up. Internal = internalizing problems. External = externalizing problems.

*$p < .05$, **$p < .01$

Table 9

Whole-Grid Descriptive Statistics for Dyadic Flexibility

		N	*M (SD)*	Median	Range
Preprocedure	Transitions	68	0.05 (0.03)	0.05	0.00 to 0.12
	Range	68	5.47 (2.04)	6.00	1.00 to 11.00
	Dispersion	68	0.46 (0.23)	0.50	0.00 to 0.82
	Flexibility	68	0.00 (1.00)	0.10	-2.28 to 2.23
	Duration (sec)	68	515.19 (104.7)	567.50	208.00 to 602.00
Procedure	Transitions	79	0.06 (0.02)	0.06	0.01 to 0.13
	Range	79	5.71 (1.82)	6.00	2.00 to 12.00
	Dispersion	79	0.55 (0.21)	0.59	0.02 to 0.87
	Flexibility	79	0.00 (1.00)	0.06	-2.50 to 2.51
	Duration (sec)	79	555.77 (97.81)	600	203.00 to 601.00

Table 10

Bivariate Correlations Among the Primary Study Variables

		2	3	4	5	6	7	8	9	10	11	12
1	Effortful Control	.40**	-.11	.11	.08	.16	-.13	.14	-.14	-.07	-.31**	-.47**
2	Ego-resilience		.05	-.04	.06	.07	-.05	.29*	-.38**	-.38**	-.28**	-.23
3	Distress			-.78**	.16	.15	.04	.22	-.08	-.30*	.06	-.20
4	Cooperation				-.11	.09	-.05	-.06	.02	.14	-.13	.03
5	Mutual pre					.52**	.50**	.28*	<.01	-.11	-.15	-.17
6	Mutual proc						.41**	.62**	-.09	<.01	-.14	-.27*
7	Flexible pre							.35**	<-.01	.10	.05	.10
8	Flexible proc								-.23	-.17	-.19	-.35**
9	Internalize T5									.63**	.64**	.33*
10	Internalize T6										.48**	.58**
11	Externalize T5											.57**
12	Externalize T6											

Note: Mutual = dyadic mutuality. Flexible = dyadic flexibility. Pre = preprocedure phase. Proc = procedure phase. T5 = 3-month follow-up. T6 = 9-month follow-up.

Table 11

Hierarchical Regression Predicting Dyadic Mutuality and Flexibility During the Preprocedure and Procedure Phase

	Mutuality preprocedure		Mutuality procedure		Flexibility preprocedure		Flexibility procedure	
Predictor	β	ΔR^2	β	ΔR^2	β	ΔR^2	β	ΔR^2
Step 1		.04		.16		.07		.07
Parent education	.11		.30*		.01		.31*	
Household income	.14		.08		-.09		.17	
Child age	.06		-.22*		-.26†		-.08	
Step 2		.004		.01		.01		.07
Effortful control	.06		.11		-.11		-.01	
Ego-resilience	.008		-.01		-.009		.28*	
Total R^2		.044		.17		.09		.14
n		75		75		64		75

†$p<.10$, *$p<.05$, **$p<.01$

Table 12

Bivariate Correlations Between Effortful Control Subscales, Separated by Age, with Dyadic Mutuality and Dyadic Flexibility

	Mutual pre	Mutual proc	Flexible pre	Flexible proc
		Ages 3 to 6[a]		
Attentional focusing	.12	.13	-.30	-.07
Inhibitory control	.15	.30*	-.16	.23
Low intensity pleasure	.03	.23	-.05	.34*
Perceptual sensitivity	.20	.28	.08	.36*
Effortful control	.16	.31*	-.16	.28
		Ages 7 to 9 years[b]		
Attentional focusing	-.22	-.03	.08	.03
Inhibitory control	-.01	-.03	.39	.05
Low intensity pleasure	.21	-.15	.05	.07
Perceptual sensitivity	-.21	.04	-.37	-.23
Effortful control	-.15	-.05	-.06	-.06
		Ages 10 to 12 years[c]		
Attention focusing	.19	.20	.33	.09
Inhibitory control	-.06	-.18	.12	-.24
Activational control	.10	.22	-.34	.24
Effortful control	.10	.12	.01	.04
		Combined across ages[d]		
Attentional focusing	-.11	-.008	.06	.10
Inhibitory control	-.01	.07	.06	.09

Note: Mutual = dyadic mutuality. Flexible = dyadic flexibility. Pre = preprocedure phase. Proc = procedure phase.

[a]$n = 39$. [b]$n = 14$. [c]$n = 14$. [d]$n = 68$.

*$p < .05$.

Table 13

Hierarchical Regression Predicting Child Distress and Cooperation

	Distress		Cooperation	
Predictor	β	ΔR^2	β	ΔR^2
Step 1		.29**		.22**
Child age	-.52**		.39**	
Treatment location	-.14		.27*	
Step 2		.07		.08
Flexible pre	-.20		.07	
Flexible proc	.28†		-.19	
Mutual pre	.17		-.22	
Mutual proc	-.14		.39*	
Total R^2		.36**		.30**
n		64		64

Note: Mutual = dyadic mutuality. Flexible = dyadic flexibility. Pre = preprocedure phase. Proc = procedure phase.

†$p<.10$, *$p<.05$, **$p<.01$

Table 14

Hierarchical Regression Predicting Child Internalizing and Externalizing Problems at 3-month and 9-month Follow-Ups

	3-month Internal		9-month Internal		3-month External		9-month External	
Predictor	β	ΔR^2	β	ΔR^2	β	ΔR^2	β	ΔR^2
Step 1		.42**		.45**		.42**		.53**
Household income	.11		-.07		.14		-.16	
Treatment site	-.001		.17		.16		.26*	
Baseline Internal	.66**		.52**		.22†		-.05	
Baseline External	.003		.14		.50**		.68**	
Step 2		.02		.03		.03		.08[a]
Flexible pre	-.02		.02		.11		.17	
Flexible proc	.04		-.14		-.01		-.28*	
Mutual pre	-.10		-.18		-.16		-.15	
Mutual proc	-.08		.24		-.08		.01	
Total R^2		.44**		.49**		.37**		.62**
n		58		51		58		49

Note: Mutual = dyadic mutuality. Flexible = dyadic flexibility. Pre = preprocedure phase. Proc = procedure phase.

†$p<.10$, *$p<.05$, **$p<.01$

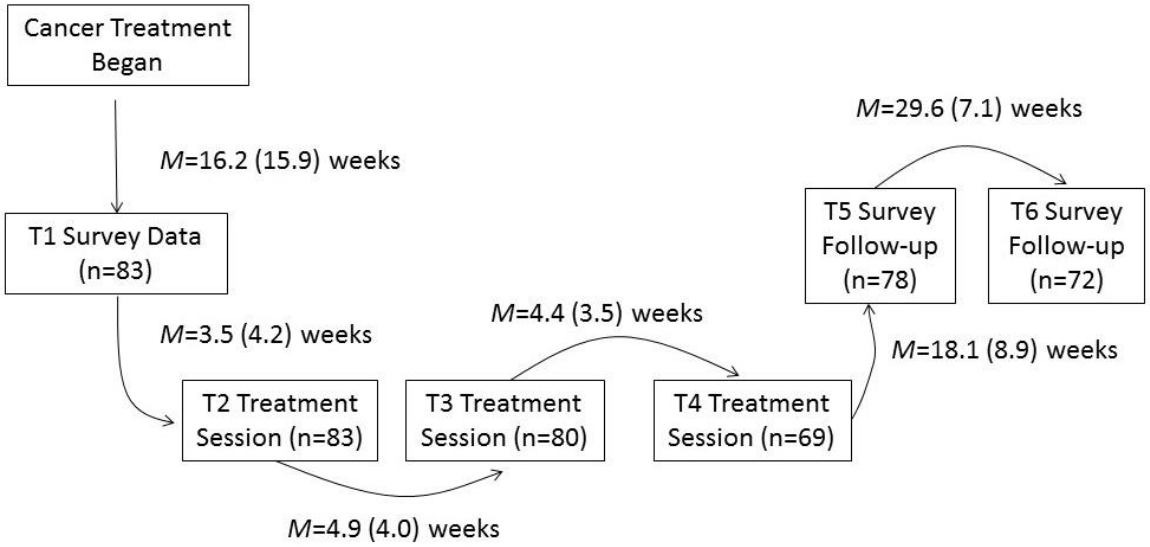


Figure 1. Study timeline.

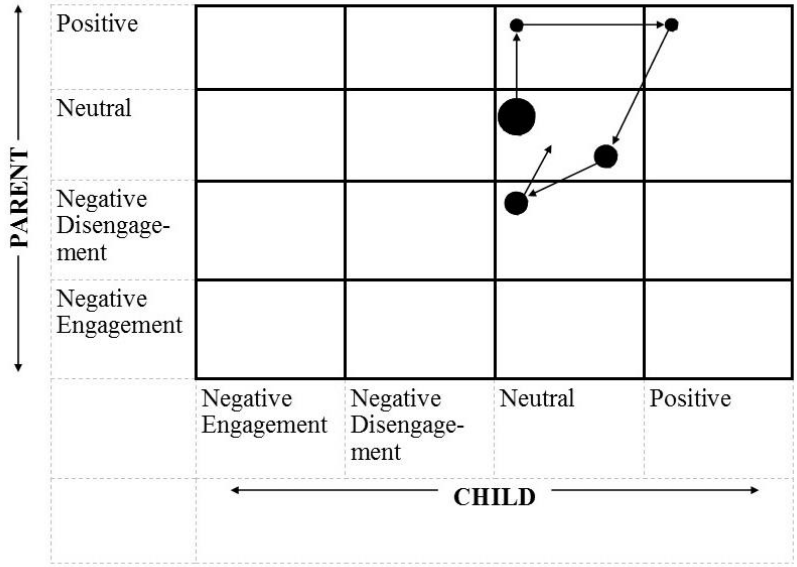


Figure 2. Hypothetical example of a state space grid. The dyad begins in the neutral-neutral cell. Transitions are represented by arrows, and the duration of each state is represented by the size of each circle.

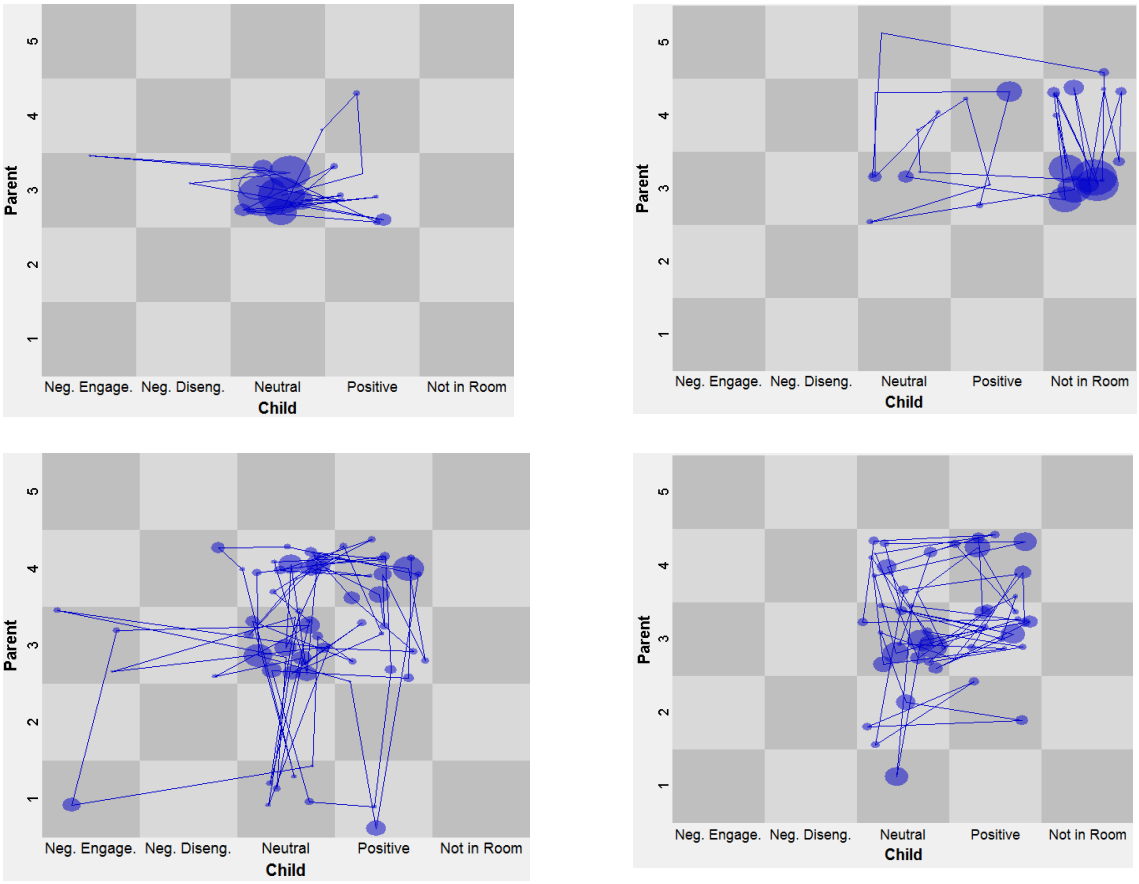


Figure 3. Examples of State Space Grids. The top-left grid demonstrates low flexibility with low dispersion and less transitions. The top-right grid demonstrates a dyad who frequently left the hospital room. The bottom-left illustrates a dyad with higher flexibility with more dispersion. The bottom-right illustrates dyad that has more transitions. The dispersion for the bottom-right would be lower because the same cells are typical re-visited.

APPENDIX A: Excerpts of Interview Conducted at Study Enrollment

ID # _____

Interview

Parent's Name _____ Date _____

Child's Name _____ Child's Age_Ch.Age_ Child's Gender__Ch.Gender____

1. When was *(child's name)* first diagnosed with cancer? Month_____Year____ Dx.Date

2. How old was he/she at that time? _____
Dx.Age

3. What was the initial diagnosis?
Dx

___ Craniopharyngioma (Brain Tumor) (01)
___ Medulloblastoma (Brain Tumor) (02)
___ Astrocytoma (Brain Tumor) (03)
___ Ependymoma (Brain Tumor) (04)
___ Brain Tumor (Unspecified) (05)
___ Brain Stem Giloma (06)
___ Ewing's Sarcoma (07)
___ (**ALL**) Acute Lymphocytic Leukemia (08)
___ (**AML**)Acute Myelogenous Leukemia (09)
___ Liver Cancer (10)
___ Wilm's Tumor (11)
___ Other _____(23)

___ Hodgkin's Lymphoma (12)
___ Non-Hodgkin's Lymphoma (13)
___ Lymphoma (Unspecified) (14)
___ Soft Tissue Sarcoma (15)
___ Extracranial Germ Cell Tumor (16)
___ Synovial Sarcoma (17)
___ Neuroblastoma (18)
___ Retinoblastoma (19)
___ Osteosarcoma (20)
___ Rhabdomyosarcoma (21)
___ Sarcoma (Unspecified) (22)
Location of sarcoma_____

5. Has ***(child's name)*** had any of the following surgeries either for treatment or diagnosis?

Port Placement	Month/Year _____ PortPlcmt
Tumor Extraction	Month/Year _____ TumExtr
Removal of organ/lymph nodes (lumpectomy)	Month/Year _____RemOrgLymp
Broviac Placement (Catheter)	Month/Year _____BrovPlcmt
Biopsy	Month/Year _____ Biopsy
Other _____	Month/Year _____ OthrSrgy

6. When did ***(child's name)'s*** most recent treatment begin; that is, the treatment s/he is currently receiving.
Month/Year _____ CrntTxStartDate

7. Has ***(child's name)*** ever received radiation therapy?
RadTx
A. Yes _1__ No _0___ (If no, go to #9)

(If yes)

B. For how long or how frequently does/did (child's name) receive radiation? (Try to get a specific answer like, for example twice a week for 6 weeks) RadTimeFreq

_____

_____

_____

9. Has (child's name) ever received a spinal tap? Yes _1__ No _0___ (if no, go to #10)
LP

(If yes)

Think back (2 month marker), how many spinal taps has s/he received since (2 month marker)? (STATE THE DATE TWO MONTHS AGO)

___ (try to get a number, be specific)
LP2Mnths

B. How many since the initial diagnosis? ____ (try to get a number, be specific) LPDx

10. Has s/he ever received a bone marrow aspiration? Yes _1__ No _0__ ***(if no, go to #11)***
BMA

(If yes)

Think back ***(2 month marker),*** how many bone marrow aspirations has s/he received since (***two month marker***)? (STATE THE DATE TWO MONTHS AGO)
BMA2Mnths

___ ***(try to get a number, be specific)***

B. How many since the initial diagnosis? ___ ***(try to get a number, be specific)***
BMAInitlDx

11. Does your child have a port? Yes _1__ No _0___ ***(if no, go to #12***)
Port

(If yes)
A. Since (***2 month marker***), has s/he had the port accessed either for a blood draw, for chemo or to be flushed? Yes _1_ No _0_ ***(if no, go to #12)***
PortAcs2mths

B. How many since ***(marker***)? ___ ***(try to get a number, be specific)***
Port2Mths
20. Adult 1: Primary Caregiver (Person completing all questionnaires for the study)

Age_ Ad1Age_ Gender_ Ad1Gen___ Relationship to Child__ Ad1Rel_____
"To which of the following racial/ethnic groups do you belong?"
Ad1Ethnicity
_1__ Hispanic/Latino
_2__ American Indian/Alaska Native
_3__ Asian
_4__ Black or African American
_5__ Native Hawaiian or Pacific Islander
_6__ White
_7__ Other (please specify) _____
8 Bi-racial (if more than one checked)

Make sure that the parent who signed the consent form is entered in SPSS as the Adult1

24. What is your current marital status?
MaritalStatus

_1__ Never Married _2__ Married _3_ Separated
_4__ Divorced _5_ Widowed _6_ Domestic Partner

25. What is the highest level of education you have completed?
Educ
_1__ No formal schooling
_2__ Elementary School (6th grade or less)_
_3__ Middle School (7th, 8th or 9th grade)
_4__ Some High School (10th, 11th, or 12th grade)
_5__ Completed High School or GED
_6__ One or two years of college (no degree)
_7__ Completed Associate's degree or Trade School
_8__ Three or four years of college or less (no degree)
_9__ Completed Bachelors Degree
_10__ Completed Masters Degree
_11__ Completed Doctoral or Professional Degree

26. Including your own income, what is the annual gross (before taxes) household income?
_1_ Less than $10,000
Income
_2__ $10,000 - $19,999
_3__ $20,000 - $39,999
_4__ $40,000 - $59,999
_5__ $60,000 – $100,000
_6__ Greater than $100,000

27. What is your current employment status?
Ad1Employ
_1__Unemployed
_2__Retired
___Employed Part-time → How are you paid _3__Hourly _4_Salary _5_Commission
___Employed Full-time → How are you paid _6__Hourly _7_Salary _8_Commission

28. (***If another adult mentioned in #21)*** What is your ***(relationship of other adult mentioned)'s*** employment status?

Adlt2Emp _1__Unemployed

_2__Retired

___Employed Part-time → How are you paid _3__Hourly _4_Salary _5_Commission

___Employed Full-time → How are you paid _6__Hourly _7_Salary _8_Commission

APPENDIX B: Excerpt of Baseline Survey for Family with Child Age 7-9

Resilience (1-11)

1.	Is resourceful in initiating activities (finds ways to make thinks happen and get things done). T1.MRES1	1	2	3	4	5
2.	Freezes up when things are stressful, or else keeps doing the same thing over and over again. T1.MRES2 **(R)**	1	2	3	4	5
3.	Is curious and exploring; he/she like to learn and experience new things. T1.MRES3	1	2	3	4	5
4.	Can bounce back or recover after a stressful or bad experience. T1.MRES4	1	2	3	4	5
5.	When under stress, he/she gives up and backs off. T1.MRES5 **(R)**	1	2	3	4	5
6.	Has specific mannerisms or behavioral rituals (e.g., has a specific habit or patterns of behavior; taps fingers, bites fingernails, stutters or bites lips). T1.MRES6 **(R)**	1	2	3	4	5
7.	Tends to get sick when things go wrong or when there is a lot of stress (for example, gets headaches, stomach aches, throws up). T1.MRES7 **(R)**	1	2	3	4	5
8.	Tends to go to pieces under stress; becomes rattled and disorganized when things go bad. T1.MRES8 **(R)**	1	2	3	4	5
9.	Can talk about unpleasant things that have happened to him/her. T1.MRES9	1	2	3	4	5
10.	Is creative in the way he/she looks at things; the way he/she thinks, works, or plays is very creative. T1.MRES10	1	2	3	4	5
11.	Uses and responds to reason (thinks things out and you can explain things to him/her like you can an adult). T1.MRES11	1	2	3	4	5
	Temperament (12-44) AF= Attentional Focusing IC=Inhibitory Control LIP=Low Intensity Pleasure PS=Perceptual Sensitivity					
12.	Is easily distracted when listening to a story. T1.MTEMP1 **(R)** AF1	1	2	3	4	5
13.	Looks around the room when doing homework. T1.MTEMP2 **(R)** AF2	1	2	3	4	5
14.	When working on an activity, has a hard time keeping his/her mind on it. AF3 T1.MTEMP3 **(R)**	1	2	3	4	5
	1 – Almost always untrue of your child 2 – Usually untrue of your child 3 – Sometimes true, sometimes untrue of your child 4 – Usually true of your child 5 – Almost always true of your child					
15.	Has a hard time paying attention. AF4 T1.MTEMP4 **(R)**	1	2	3	4	5
16.	Needs to be told by teacher to pay attention. AF5 T1.MTEMP5 **(R)**	1	2	3	4	5
17.	Needs to be told to pay attention. T1.MTEMP6 **(R)** AF6	1	2	3	4	5
18.	Gets distracted when trying to pay attention in class. T1.MTEMP7 **(R)** AF7	1	2	3	4	5
19.	Can stop him/herself when s/he is told to stop. T1.MTEMP8 IC1	1	2	3	4	5

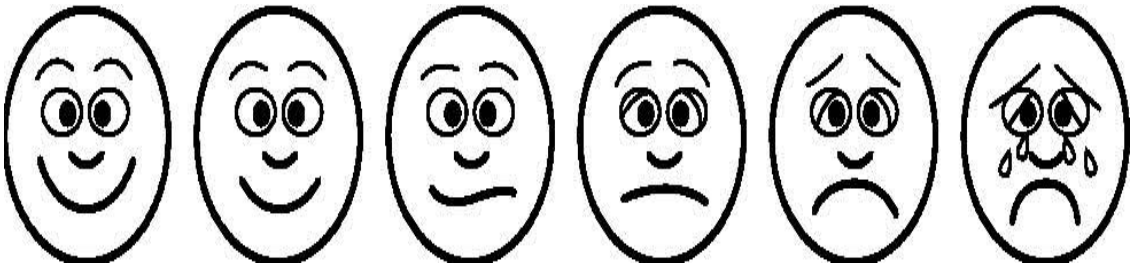
20.	Can stop him/herself from doing things too quickly. T1.MTEMP9 IC2	1	2	3	4	5
21.	Has an easy time waiting to open a present. T1.MTEMP10 IC3	1	2	3	4	5
22.	Has a hard time waiting his/her turn to talk when excited. T1.MTEMP11 **(R)** IC4	1	2	3	4	5
23.	Is very careful and cautious when crossing the street. T1.MTEMP12 IC5	1	2	3	4	5
24.	Likes to plan carefully before doing something. T1.MTEMP13 IC6	1	2	3	4	5
25.	Is able to keep secrets. T1.MTEMP14 IC7	1	2	3	4	5
26.	Has a hard time slowing down when rules say to walk. T1.MTEMP15 **(R)** IC8	1	2	3	4	5
27.	Likes the crunching sound of leaves in the fall. T1.MTEMP16 LIP1	1	2	3	4	5
28.	Likes to play quiet games. T1.MTEMP17 LIP2	1	2	3	4	5
29.	Likes the sound of poems. T1.MTEMP18 LIP3	1	2	3	4	5
30.	Enjoys looking at books. T1.MTEMP19 LIP4	1	2	3	4	5
31.	Likes quiet reading time. T1.MTEMP20 LIP5	1	2	3	4	5
32.	Likes the feel of warm water in a bath or shower. T1.MTEMP21 LIP6	1	2	3	4	5
33.	Likes to look at trees. T1.MTEMP22 LIP7	1	2	3	4	5
34.	Likes to sit under a blanket. T1.MTEMP23 LIP8	1	2	3	4	5
35.	Notices the color of people's eyes. T1.MTEMP24 PS1	1	2	3	4	5
	1 – Almost always untrue of your child 2 – Usually untrue of your child 3 – Sometimes true, sometimes untrue of your child 4 – Usually true of your child 5 – Almost always true of your child					
36.	Notices the sound of birds. T1.MTEMP25 PS2	1	2	3	4	5
37.	Notices odors like perfume, smoke and cooking smells. T1.MTEMP26 PS3	1	2	3	4	5
38.	Can tell if another person is sad or angry by the look on their face. PS4 T1.MTEMP27	1	2	3	4	5
39.	Touches fabric or other soft material. T1.MTEMP28 PS5	1	2	3	4	5
40.	Notices small changes in the environment, like lights getting brighter in a	1	2	3	4	5

	room. PS6 T1.MTEMP29						
41.	Notices things others don't notice. T1.MTEMP30 PS7	1	2	3	4	5
42.	Notices even little specks of dirt on objects. T1.MTEMP31 PS8	1	2	3	4	5
43.	Likes to run his/her hand over things to see if they are smooth or rough. PS9 T1.MTEMP32	1	2	3	4	5
44.	Notices when parents are wearing new clothing. T1.MTEMP33 PS10	1	2	3	4	5

APPENDIX C: Treatment Sessions: Excerpts of Parent Postprocedure Survey

Faces-Parent Distress

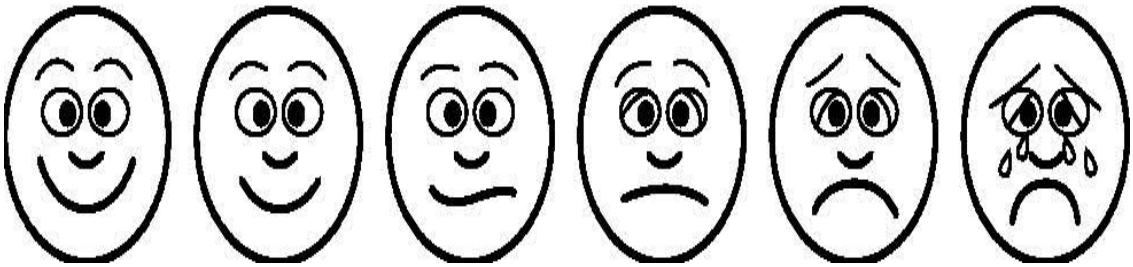
The next set of faces below represent different levels of distress that **you** might have experienced today. Please circle the number that comes closest to your judgment of how much distress **you experienced today**. Please note: We are interested in your distress today, not your general level of distress.



No Distress at All	**A Little Bit of Distress**	**A Little More Distress**	**Even More Distress**	**A Whole Lot of Distress**	**The Worst Distress**
1	2	3	4	5	6

Faces-Parent Report of child's Distress

The next set of faces below represent different levels of distress that **your child** might have experienced today. Please circle the number that comes closest to your judgment of how much distress the child experienced today. Please note: We are interested in his/her distress today, not his/her general level of distress.



No Distress at All	**A Little Bit of Distress**	**A Little More Distress**	**Even More Distress**	**A Whole Lot of Distress**	**The Worst Distress**
1	2	3	4	5	6

Child Cooperation

Please rate the extent to which the child cooperated with completing today's treatment-related procedure. Please circle the number that comes closest to your judgment of how cooperative the child was with today's treatment-related procedure. "1" means the child was "Totally Uncooperative" and "7" means the child was "Totally Cooperative."

PCOOP

Totally Uncooperative						Totally Cooperative
1	2	3	4	5	6	7

1 2 3 4 5 6 7

Check all the following that apply:

Today's Procedure

Today's treatment-related procedure was:

_1__ Port Start __1_ Numbing cream __4_ Numbing spray _5_Nothing

_2__ Lumbar Puncture __2_ General Anesthesia _3_Awake

_3__ Bone Marrow Aspiration __2_ General Anesthesia _3_Awake

APPENDIX D: Valence Coding for Pediatric Hospital Visits

Manual created by
Benjamin Goodlett

Input and revisions provided by
Samantha Cloutier and Chris Yoo

Updated 2.15.17

Purpose & Background

- This coding system is based on Hollenstein et al (2004) use of the Specific Affect Coding System (SPAFF) manual developed by Gottman and colleagues (Coan & Gottman, 2007)
- The purpose is to record the emotional state and changes in emotional state for both a parent and child while they are waiting in a hospital room for the child to undergo a port start. The individual specific codes included in the SPAFF manual are collapsed to four categories based on findings by Hollenstein et al that the indices of variability in emotional state do not change when collapsing from the specific to the broader categories.
- Verbal behavior, physical behavior, and affective tone are taken into account to estimate overall affective state. For example, "What do you mean?" could be coded as Neutral or Negative Emotion Valence depending on the emotional tone. Silence or a very neutral discussion could be coded as positive if the parent is expressing warmth by holding the child's hand or rubbing their head.
- Coding is done in real time. It is possible that multiple emotions, in different categories, can be displayed at the same time. For example, a parent may express exasperation (Negative) along with affection (Positive). A coding hierarchy is therefore necessary. This project uses a hierarchy that is based on the salience of different emotional displays.
    1. Negative Engagement
    2. Negative Disengagement
    3. Positive
    4. Neutral
- The guiding principle in a coders decision should be their overall sense of a Positive, Neutral, or Negative emotional state for the parent/child. This manual includes the specific SPAFF codes and examples as a reference for the coder if they are uncertain which category is most appropriate.

Coding Rules

- Coding is based on the combination of voice tone, facial expression, body language, behaviors, and content of conversations.
    - The goal is to code the overall affective tone using facial expression, gestures, posture, voice tone and volume, speech rate, and verbal/motor responses.
- Use of the overall tone of a video
    - Use the overall emotional tone of the video as context for specific interactions. For example, a request may sound stern and therefore possible Negative Engagement. Consider how other requests and non-requests have been phrased.
- "Sticky coding"

- 3 second rule: The focus of coding is not rapid fire shifts where word-by-word emotional valence switches between categories. Additionally, the onset of a code is not likely to line up exactly with the onset of a behavior because the coder has to recognize, identify, and respond before the code onset occurs.
  - Onset times need to be as close as possible to when a behavior begins, but they will likely not much up *exactly*.
  - Some leeway should be used when switching from Negative or Positive back to Neutral. Unless there is a clear shift in emotional state. Give three seconds before switching from negative or positive back to neutral
- Example: If parent is using a chipper tone of voice and making statements which have positive content then the code remains Positive Valence if they pause to allow the other person to talk.
  - Primary caregiver "She really did a great job"
    Other adult "I'm glad to hear that."
    Primary caregiver "I'm so proud of her.
    - The whole interaction is coded as Positive Valence for the primary caregiver even though there is a pause in her talking while the other adult talks.
-

- The SPAFF coding system was originally developed for one-on-one conversations between married couples, and codes were also based on communication from one partner to the other. Videos for this study often include the child, a caregiver, possibly medical staff, and possibly other family members (adults or children). ***Code emotional displays for the child and parent regardless of who they are directed at. For example, if the child and medical staff are joking with each other then the child's valence should be coded as Positive Engagement (for Humor).
- Identifying primary caregiver – If more than one adult family member is in the room then the PARCHISY coding sheet should indicate which parent is the primary caregiver.

Coding Procedure

- Connect to Mira: afp://mira.kci-net.karmanos.org Either use your login or ask Ben Goodlett to log you into Mira.
- Valence coding:
  - The real-time coding is completed using StudioCode.
  - Coding is conducted in two "passes". The PARCHISY coding sheet should indicate whether to complete the parent or child pass first.
  - The code for each valence is based on the overall verbal content, affective tone, and physical behavior of a person. Codes can be based on only one aspect of a person's behavior. For example, a parent praising their child in a neutral tone and no physical contact would be coded as Positive Valence.
  - People may also present multiple behaviors within the same category. For instance, a parent may tell their child they love them while rubbing their child's back. Both behaviors are consistent with Positive Valence and that overall code would capture the interaction.
  - It is possible that codes in multiple affective valences are displayed at once. For those instances, it is necessary to record a single affective valence.

  - Negative behaviors are more salient than neutral or positive behaviors. Therefore, negative behaviors are given highest priority.
  - Positive behaviors given in conjugation with neutral behaviors shape the tone of the interaction. Therefore, positive behaviors are given higher priority than neutral behaviors

- PARCHISY: Complete global ratings immediately after watching both passes of the video. You may check the individual item definitions after you have completed all of the global ratings. Definitions and rating insructions for PARCHISY are provided in this manual after the SPAFF.

Engagement vs Disengagement: Child is whining about taking off his or her shirt (Negative Disengagement) then pushes away parents hands (Negative Engagement).

Real-Time Codes

Negative Valence

All Negative Valence codes are split between Negative Engagement and Negative Disengagement. The split between engagement and disengagement is based on the social function each type of negative affect reflects (Hollenstein, Granic, Stoolmiller, & Snyder, 2004).

Negative Physical.

Nonverbal disapproval: any actions that clearly indicate disapproval, or negative regard, are coded as Negative Valence. For example, a family member sticking a tongue out, making a face of contempt or disgust, or giving the finger would be recorded as one of the negative valence codes.

Intrusive Physical Contact: Any contact with another person including light hitting, pinching, slapping, ear flicking, grabbing another's hand, kicking or shove. Negative Physical involves any physical contact that is intended to be unpleasant and/or aversive (e.g. kicking a family member's chair). NOTE: It is common for parents to restrain their child during medical procedures. If the child is okay with the restrain Negative Valence is not coded.

Objects: Throwing or using objects with the intention to harm or threaten is coded as Negative Valence. Destruction of objects is also coded as Negative Valence. NOTE: Child tearing of paper *with permission* is not coded as Negative Valence.

Negative Engagement

SPAFF codes: Anger, Disgust, Contempt, Criticism, Belligerence, Domineering, Threats,

Examples

- "I'm gonna pop you." (Anger/Threats)
- "Stop slamming the trashcan." (Negative Tone)
- "No don't do that," while parent pulls away child's hand.
- Child uses physical force (e.g., pulling, pushing) to resist medical procedure.
- Statements that the child's medical procedure, or the child's resistance to the procedure, is inconveniencing the parent. Example: Mom uses exasperated tone, "I'd like to go see my mother."

Anger functions to respond to perceived violations of the speaker's rights to autonomy and respect. It serves as a kind of "affective underlining" of displeasure and complaint, indicating that an interpersonal boundary has been transgressed.

- Discipline and scolding.
- Child shouts, "NO!"

Disgust is a relatively involuntary verbal or nonverbal reaction to a stimulus that is perceived to be noxious. Harmful substances (e.g., feces, rotted food) reliably elicit disgust, but disgust can also occur for moral or symbolic reasons (Rozin, Lowery, & Ebert, 1994).

The function of **Contemptuous** behavior is to belittle, hurt, or humiliate.

- Any gender shaming from the parent is Contemptuous. Example: "Don't be a little girl."
- Example: Child points out to the medical staff that his parent did not wait to eat but his brother did.
- Hostile humor example: Mom to medical staff, "He's trying to run away from the chemo," while the child is crying.

Criticism functions as an attack on someone's character or personality in a way that is not obviously insulting, as in Contempt.

- Example: Parent complaining about the tissues at the hospital.

The function of **Belligerence** is to "get a rise" out of the receiver through provocation of anger.

- Child says sarcastic remarks that the parent needs the medical procedure (e.g., receive a needle stick).

The function of **Domineering** behavior is to exert and demonstrate control over one's partner or a conversation

- Example: Negative tone combined with "Stop it"
- Example: Parent issues a directive, child is unresponsive, and the parent issues the command again with a negative tone (Parent – Domineering)

Threats are a particularly hostile form of domineering behavior in that their function is to control the behavior of the receiver by setting explicit conditions under which the receiver will be punished for behaving in ways the speaker finds undesirable.

Counter indicators
1. Good-natured teasing. Good-natured "jabs" at the receiver's foibles are not coded as belligerence, especially if the humor or the teasing appears to be
shared.

Negative Disengagement (from Coan & Gottman, 2007; Hollenstein et al., 2004)

SPAFF codes: Sadness, Stonewalling, Fear/Tension, Whining, Defensiveness

The **Sadness** code refers to behaviors that communicate loss, resignation, helplessness, pessimism, hopelessness, or a plaintive inactivity.

Stonewalling: functions to communicate an unwillingness to listen or respond to the receiver.

- Example: Child makes a show of ignoring a parent request.
- Example: Child takes an overly-literal interpretation of a parent request in order to not comply "Let me see for a second." Child responds by quickly showing, but not handing parent the object.

- Not an example: For young children, developmentally appropriate emotion regulation should be considered. If the child is being chastised; is listening; but is engaged in another activity while listening; then, coder needs to determine if child is listening to parent but using activity to regulate their emotions. Stonewalling is reserved for obvious displays of not paying attention.
- Example: Child ends conversation with a nurse by turning away.
- Example: Nurse asks child to move/laydown on the medical table and the child does not move or comply.
- Example: Child goes limp or stiff as the nurse tries to prep for the procedure.

Fear/Tension communicates, usually involuntarily, fear, worry, anxiety, nervous anticipation, or dread.

- Fear/Tension in reaction to the medical appointment is often present with Whining.

Whining functions to make what might otherwise be an ordinary complaint into a plaintive or pleading form of emotional protest. Whining suggests an innocent victim stance, communicating something like "What are you picking on me for?" or "What about all the good I do?"

- Child, "No, I want to go to the bathroom by myself!"
- Child, (drawn out) "Noooooooo".

Defensiveness functions to deflect responsibility or blame. It communicates a kind of innocent victimhood or righteous indignation (e.g., as a counterattack) on the part of the speaker, implying that whatever bad thing being discussed is not the speaker's fault.

Stonewalling

Examples

- "I didn't do anything" (Whining).
- Parent or staff: "Are you reading?" Child: "No" (Tone of voice or body language should communicate the child wants the conversation to end).
- Child continues to play video game while not responding to parent (Stonewalling)

Positive Valence

SPAFF Codes: Interest, Validation, Affection, Humor, and Enthusiasm

Affection expresses genuine caring, concern, tender, or offers comfort. Often the voice slows and becomes quieter or lower. Its function is to facilitate closeness and bonding. Parent pulling child into their lap.

- Parent rocking distressed child
- Child sitting in parent's lap is likely, but not necessarily, affection. At times child will be asked to sit in parents lap before the procedure and sitting in the parent's lap may be purely instrumental
    - Other signs of physical affection to look for: rubbing arm, back, or head; kisses; reassuring vocal tone or words.
    - Sitting in lap and parental attention (e.g., looking at child or child's activity with interest) is Positive Engagement.

    - If child tries to pull away, resists, or fights with parent while in the parents lap code Negative Engagement for child and parent.
- Ex. of comfort: Parent asking child if they need something like a blanket or toy.
- Ex. concern and comfort parent says "Oh you got a boo boo"

Humor is amusement and joy which often involves a mutually recognized moment of absurdity or fun.
- Activities that count as humor: good-natured teasing, wit and silliness, private jokes, fun and exaggeration, and nervous giggling.
- The original SPAFF system required Humor to be a *shared* activity.
- Teasing that is mutually shared as fun is coded as Humor.
- Silly physical activities: Parent looks in child's ear to find the blowing bubbles.
- Play fighting – This could be verbal (teasing) or non-verbal (tickling).
- Parent or child laughing together or individually. For example, if a parent laughs at their own joke.

Enthusiasm is to express a passionate interest in a person or activity, as well as a positive valence associated with that interest. Enthusiasm is infectious and often sudden, loud, boisterous, and energetic. Nonverbal behaviors prominently accompany verbal expressions of eagerness and joy. Child playing with toys energetically. Needs to be more than "just" playing. Child may make happy noises or have a high level of activity.
- This code often occurs when parents/children are discussing a prized possession, accomplishment, or experience. E.g. talks about vacation.
- Child explaining a thing or activity they are excited about is often Enthusiasm. E.g., Child talking about why they like Halloween or describing a favorite TV show.
- Child yells or is being loud in excitement: "Woo!" "Look!" "This one goes fast!"
- Child playing with toys energetically. Child could have a high activity level while playing, be making happy noises, or sharing play/toys with others.

Validation is to communicate sincere understanding and acceptance of one's partner or of one's partner's views and opinions. In the SPAFF, Validation is considered to be a positive valence behavior.
- Parent reflecting what child says with a positive tone is Positive Engagement.
- Apologies: "I'm sorry you have to do this"; "I'm sorry, you're right"

Interest. The function of this behavior is to communicate genuine interest in one's partner through seeking elaboration or clarification. As used in the SPAFF, Interest is characterized as a positive valence behavior that emphasizes information gathering about the partner as opposed to minor or trivial factual information. For parent-child dyads, this code is often present for the parent while the child is engaged in a pleasurable activity (e.g., playing).
- **Attention** combined with vocal tone is an important aspect of expressing positive affect to children.
- Genuine interest: attend to the parent's body language and tone as well as the child's responses.
- Example: Mom bends over to look at child's Legos and asks him what he is making.
- Example: Parent watches child drawing on a white board and asks her what she is drawing.

- Example: Parent leans over child to watch what the child is doing (often child is playing).

Satisfaction (Not part of original SPAFF system). Behaviors which demonstrate satisfaction or being content are coded as positive. This code was created to account for a child's reaction after being handed a desired toy or object.

Positive Physical Non-verbal actions that clearly indicate approval or positive regard are coded Positive Valence.

- Examples of positive parent behaviors, rubbing the child's back or head, hugs, kisses, embraces, or holding the child's hand.
- Examples of positive child parent behaviors, leaning in to parent (while standing or sitting in parent's lap)
- Child on parents lap: Note that some procedures are conducted with the child sitting in the parents lap. If the child in the parents lap appears to be for procedural purposes this might not be coded as positive valence.

Counterindicators are instances which should not be coded as Positive Valence

1. *Defensive affection*. Occasionally, a speaker will insist that he loves the receiver as a defensive maneuver. The indicators of defensiveness (discussed in Negative Disengagement) will usually give this away. Watch for defensive voice tone, a defensive context, and a lack of warm, positive feeling underlying the affectionate message.
2. *Negative Surprise*. Surprise reactions are not unequivocally positive, and it is important to be watchful for surprise reactions that contain either a lack of positive affect or the presence of negative affect.
3. *Tense humor*. Humor that is obviously both a nervous reaction to a high level of tension in the conversation and either lacking in any positive energy or unshared.
4. *Contemptuous humor*. Jokes that are intended to be hurtful or insulting and that are unshared. This is sometimes confused with teasing. A good rule for distinguishing contemptuous humor from good natured teasing is to attend closely to the degree to which both individuals are amused.

Neutral Valence

- Inactivity is coded as Neutral Valence.
- Any behaviors which do not meet the criteria for a Positive or Negative Valence behavior are coded as Neutral.

Examples:

- Child playing quietly with toys.
- Parent is engaged in a solo activity such as reading or looking at their phone.

Physical contact any physical contact between two people which is inherently neutral or non intrusive. This code also includes any low-grade physical contact with another person that is not delivered with the intention to harm such as a child inadvertently hitting a parent while embracing.

- Child sitting in the parent's lap is neutral unless obvious Positive Physical Contact (e.g., patting or rubbing back), or the parent is also engaged in verbal behavior which is in the Positive Valence.
- NOTE: If a parent is physically restraining the child but the child is not resisting then this is Neutral Physical Contact.

Not Codable

If the door the hospital room is open and a person is not visible on camera then "Not Codable" is used. You may be able to clearly hear the person. However, if you are not sure that the person is in the room then you may not know if silence is the person out of range to be heard or not. Therefore, if the person *may* not be in the room and you cannot see them then "Not Codable" is the appropriate code.

Global Codes

(adapted from)

PARCHISY: PARENT CHILD INTERACTION SYSTEM GLOBAL RATINGS FOR THE ETCH-A-SKETCH TASK

Kirby Deater-Deckard, Maria V. Pylas, & Stephen A. Petrill
Institute of Psychiatry & Institute of Education, University of London

May 1997

 Address correspondence to Kirby Deater-Deckard, Department of Psychology—Virginia Tech, 109 Williams Hall (0436), Blacksburg, VA, 24060; kirbydd@vt.edu

Global Coding Instructions

- Rate each of the global codes immediately after watching the video. Make an initial rating and consult the coding instructions after you have completed each global rating.
- Codes are based on both duration AND intensity of codes. For instance 45 seconds of cussing and hitting a family member would be coded at a 7 out of 7 for negative affect.
- NOTE: Video-tapes with limited interaction between parent and child will likely result in low scores for *both* positive and negative affect.

PARCHISY Response scale		
1	None	No occurrences
2		At least one instance regardless of intensity.
3		More than one occurance.
4	Moderate	Low intensity for the majority of the video.
5		
6		
7	A lot (the most)	Long duration and several high intsnsity. The behavior's intensity & duration is at the highest level expected for the situation. It would be hard to imagine other parents engaging in the behavior more.

1, 2-3, 4, 5-6, 7 are determined by frequency. Then 2 or 3; 5 or 6 are determined by intensity.

Parent Ratings

1. Positive affect (warmth): smiling, laughing, tender, comforting, encouraging, praise

2. Negative affect - rejection: frowning, cold/harsh voice, frowning, stern looking, harsh/cold voice, threatening.

3. Responsiveness to child's questions, comments, behaviors

- expands on some comments made by child;

- responds to child's comments, questions, and behaviors, although some responses may be delayed
- Responsiveness is not necessarily a positive behavior. Any response, positive or negative, to a behavior or comment by other dyad member is considered responsiveness.
- Responsiveness can be verbal or non-verbal. For example, a child request for a child may be *responded* to by the parent by handing the child the toy. This action may or may not be accompanied by talking or vocalization.
- Responsiveness can occur in response to direct bids for attention or in response to a behavior not directed at the other member of the dyad. Example: Child playing too loudly is likely to be followed by a response from their parent. A lack of a parent response is likely to be an example of low responsiveness.

Child Ratings

1. Positive affect (warmth): smiling, laughing
- smiling, laughing for about half of interaction

2. Negative affect - rejection: frowning, cold/harsh voice tones
- frowning, stern looking, harsh/cold voice for about half of interaction
- always scowling/frowning, voice always in harsh tones

3. Responsiveness to mother's questions, comments, behaviors: responses can be either verbal or behavioral

Dyadic Codes

1. Reciprocity: shared positive affect, eye contact, a "turn taking" (ie. conversation-like) quality of interaction. Dyads with high reciprocity have long peridods of positive affect, shared attention, and often with a "turn taking" quality.

2. Conflict: minor or major disagreement - mutual or shared negative affect; arguing, tussling over toy, etc.

PARCHISY Global Rating Response Sheet

Coder______ **Date________**

Tape ID _____ **Video Start Time ______** **Video Stop Time____**
Parent **First Pass ____________**

Parent							
Positive Affect	1	2	3	4	5	6	7
Negative Affect	1	2	3	4	5	6	7
Responsiveness to Child	1	2	3	4	5	6	7
Child							
Positive Affect	1	2	3	4	5	6	7
Negative Affect	1	2	3	4	5	6	7
Responsiveness to Parent	1	2	3	4	5	6	7
Dyad							
Reciprocity	1	2	3	4	5	6	7
Conflict	1	2	3	4	5	6	7

Tape ID _____ **Video Start Time ______** **Video Stop Time____**
Parent **First Pass ____________**

Parent							
Positive Affect	1	2	3	4	5	6	7
Negative Affect	1	2	3	4	5	6	7
Responsiveness to Child	1	2	3	4	5	6	7
Child							
Positive Affect	1	2	3	4	5	6	7
Negative Affect	1	2	3	4	5	6	7
Responsiveness to Parent	1	2	3	4	5	6	7
Dyad							
Reciprocity	1	2	3	4	5	6	7
Conflict	1	2	3	4	5	6	7

Tape ID _____ **Video Start Time ______** **Video Stop Time____**
Parent **First Pass ____________**

Parent							
Positive Affect	1	2	3	4	5	6	7
Negative Affect	1	2	3	4	5	6	7
Responsiveness to Child	1	2	3	4	5	6	7
Child							
Positive Affect	1	2	3	4	5	6	7
Negative Affect	1	2	3	4	5	6	7
Responsiveness to Parent	1	2	3	4	5	6	7
Dyad							
Reciprocity	1	2	3	4	5	6	7
Conflict	1	2	3	4	5	6	7

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ABSTRACT

PARENT-CHILD INTERACTION STYLE AND ADJUSTMENT TO PEDIATRIC CANCER TREATMENT

by

BENJAMIN D. GOODLETT

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Advisor: Dr. Christopher J. Trentacosta

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Degree: Doctor of Philosophy

Substantial gains in the survival rate of children diagnosed with cancer have been achieved; however, a large body of evidence exists that children and their families are at increased psychosocial risk. Missing from our understanding is how real-time, moment-to-moment interactions build to long-term, developmental changes in child functioning. This project expands our understanding of the variation in child distress during procedures as well as long-term adjustment. Real-time coding and global ratings of parent and child behaviors were used to describe parent-child interactions in terms of dyadic flexibility and dyadic mutuality.

To carry out this project, a new system of collecting data needed to be created or an existing system needed to be adapted. Based on previously published examples and pilot testing, two systems were selected for adaptation for the current project. The SPAFF is a real-time coding system that uses a holistic approach of integrating verbal statements, non-verbal behaviors, and tone of voice to create an overall label of emotional state (Coan & Gottman, 2007; Lunkenheimer et al., 2011). This system was used to examine emotional flexibility in a parent-child dyad during a hospital visit for a port start procedure that was part of the child's cancer treatment regimen. Dyadic mutuality was adapted from the PARCHISY (Deater-Deckard

et al., 1997) which uses global ratings of parents and children. The specific aims of this study were Aim 1: evaluate the implementation of the coding and rating system in a hospital setting, Aim 2: examine the association between child temperament and the observations of the parent-child dyad in the hospital room, Aim 3: investigate the association between parent-child hospital room behaviors and child distress & cooperation during the procedure, and Aim 4: assess the predictive ability of parent-child hospital room behaviors on long-term child internalizing and externalizing problems.

The overall findings of this study support a model in which child ego-resilience is associated with parent-child hospital room behaviors. Parent-child hospital room flexibility and mutuality are associated with long-term child externalizing problems. These findings are consistent with previous work from the same research sample as well as the general child development literature.

AUTOBIOGRAPHICAL STATEMENT

Benjamin Goodlett received a Bachelor's of Science in Psychology from the University of South Carolina Honors College in 2008. In the fall of 2009, he entered the Clinical Psychology doctoral program at Wayne State University. He completed his Master of Arts degree with a major in Clinical Psychology in the spring of 2013. Dr. Christopher Trentacosta was the chair of his Master's Thesis "Adolescent Characteristics and Peer Influence as Predictors of Antisocial Behavior in Males." Through his work with Dr. Trentacosta, Ben pursued his interest in observational research of parent-child and peer interactions that contribute to the development of conduct problems. While a graduate student, Ben worked with Drs. Louis Penner and Felicity Harper at the Barbara Ann Karmanos Cancer Institute on a longitudinal study of child and family functioning during pediatric cancer treatment.

Ben completed an APA-accredited pre-doctoral internship at Baylor College of Medicine, Menninger Department of Psychiatry and Behavioral Sciences – Texas Children's Hospital track. He further developed his interest in family functioning in the context of child adverse health conditions through his clinical work. Currently, Ben is working in the Metabolism Clinic at Boston Children's Hospital under the attending supervision of Dr. Susan Waisbren. Ben is continuing his research and clinical interests through working with the Urea Cycle Disorders Consortium to improve our understanding of and clinical services for children with urea cycle disorders.