PARENT DISTRESS, PARENT-CHILD INTERACTIONS, CHILD DISTRESS AND CHILD COOPERATION DURING CANCER TREATMENT–RELATED PORT STARTS: A CARING PERSPECTIVE

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ABSTRACT

JINBING BAI: Parent Distress, Parent-Child Interactions, Child Distress and Child Cooperation during Cancer Treatment–Related Port Starts: A Caring Perspective
(Under the direction of Sheila J. Santacroce)

Children reported more suffering from cancer treatment−related painful procedures than cancer itself. Appropriate parent interaction behaviors can help children cope with these painful procedures. Swanson's Theory of Caring provides a framework to formulate parent interaction behaviors. This dissertation consisted of three separate papers to investigate parent-child interactions during cancer treatment−related port starts.

The first paper reviewed 15 extant observational coding systems of parent-child interactions during painful procedures. These measures had at least an acceptable reliability and some evidence for validity. Only two coding systems were informed with clear theoretical foundations. Parent nonverbal behaviors were under-represented especially for older children (ages 3–18 years). Four of the coding systems were evaluated well-established measures.

The second paper reported the development of the Parent Caring Response Scoring System (P-CaReSS) by the hybrid approach of inductive and deductive coding and tested its psychometric properties. The 18-item P-CaReSS assesses parent verbal (11 items), nonverbal (6 items), and emotional behaviors (1 item). It is feasible to develop an observational measure based on Swanson's Theory of Caring. The P-CaReSS has acceptable inter-rater reliability and construct validity for use during cancer painful procedures.

The third paper explored the change of parent interaction behaviors over time and the temporal relationships between parent interaction behaviors and child distress during repeated

port starts procedures. We found that more parents significantly displayed nonverbal caring behaviors over time and parent verbal caring behaviors did not change significantly. Sequential analyses showed that children were significantly less likely to display verbal and behavioral distress following parent caring behaviors than at any other time. If a child is already engaged with distress, parent verbal and nonverbal caring behaviors can significantly reduce child verbal and behavioral distress.

This dissertation adds new knowledge to current literature in two ways−validating the impact of theory-based parent caring behaviors on child treatment−related responses by sequential analyses and providing new solutions to design evidence-based interventions during cancer procedures. Future studies are needed to explore the moderators of the relationships between parent-child interaction behaviors and intervention programs can be developed to facilitate parents to use caring verbal and nonverbal behaviors.

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LIST OF ABBREVIATIONS

ALL	Acute lymphocytic leukemia
BAADS	Behavioral Approach-Avoidance and Distress Scale
BMA(s)	Bone marrow aspiration(s)
CAMPIS	Child-Adult Medical Procedure Interaction Scale
CAMPIS-IV	Child-Adult Medical Procedure Interaction Scale-Infant Version
CAMPIS-R	Child-Adult Medical Procedure Interaction Scale-Revised
CAMPIS-SF	Child-Adult Medical Procedure Interaction Scale-Short Form
CBCS-P	Child Behavior Coding System-Post Anesthesia Care Unit
CI(s)	Confidence Interval(s)
CINAHL	Cumulative Index to Nursing and Allied Health Literature
CSF	Cerebral spinal fluid
CVI	Content validity index
DPIS	Dyadic Pre-stressor Interaction Scale
EMLA	Eutectic mixture of local anesthetics−prilocaine and lidocaine
GEE	Generalized estimating equation
GRIDS	Generation R Infant Distress Scale
GSEQ	General Sequential Querier Program
HaPI	Health and Psychosocial Instruments
HIPAA	Health Insurance Portability and Accountability Act
IASP	International for the Study of Pain
IAS(s)	Interaction analysis system(s)
ICC	Intra-class coefficient

IOM	Institute of Medicine
IQR	Interquartile Range
IRB(s)	Institutional Review Board(s)
IRR	Inter-rater reliability
IV	Intravenous
K-CCD	Karmanos Child Coping and Distress Scale
LP(s)	Lumbar puncture(s)
MAISD	Measure of Adult and Infant Soothing and Distress
mos.	Months
NA	Not applicable
NI	None indicated
NIH	National Institute of Health
OR(s)	Odds ratio(s)
OSBD	Observational Scale of Behavioral Distress
PACBIS	Perioperative Adult Child Behavioral Interaction Scale
PACU	Post-Anesthesia Care Unit
P-CAMPIS	Perioperative Child-Adult Medical Procedure Interaction Scale
P-CaReSS	Parent Caring Response Scoring System
PI	Principal investigator
PRC	Protocol Review Committee
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
PTSS	Post-traumatic stress symptoms
RA	Research assistant

SPP-ATF	Society of Pediatric Psychology Assessment Task Force
SD	Standard deviation
VAD	Venous access device

CHAPTER 1. PARENT-CHILD INTERACTIONS DURING CANCER TREATMENT−RELATED PAINFUL PROCEDURES

Background

Cancer, a major public health problem in the United States, is the second most common cause of death in children and adolescents (Siegel, Naishadham, & Jemal, 2013). Approximately 12, 400 children are diagnosed with cancer each year in the United States (American Cancer Society, 2013; Pizzo & Poplack, 2010, p.1256) and the incidence of childhood cancer has been increasing by 0.5% per year (Siegel et al., 2013). However, with the development of multi-modal therapies (i.e., surgery, chemotherapy, radiation therapy, hematopoietic stem cell transplant, and biological response modifiers), aggressive anticipatory supportive care, and specialty nursing, the 5-year survival rate for children with cancer in the United States has increased from 58% during the mid-1970s to 83% today (American Cancer Society, 2013).

Children being treated for cancer require regular monitoring for disease extension or recurrence, treatment effectiveness, and treatment toxicities or side effects. This monitoring is done by laboratory assays of body tissue samples that are obtained through one of several means: cerebral spinal fluid (CSF) is obtained via lumbar punctures (LPs); cells in the bone marrow that produce various blood components are obtained via bone marrow aspirations (BMAs); and blood is obtained via venous access device (VAD) puncture, which is commonly referred to as a "port start" when used to establish intravenous (IV) access through which chemotherapies and supportive care agents can be delivered that day or in the near future (Blount, Piira, Cohen, & Cheng, 2006; Pizzo & Poplack, 2010, p. 1263). These invasive procedures can occur in clusters

within a relatively short period of time—for example, during diagnostic evaluation and treatment initiation—and repeated at regular intervals as determined by the child's clinical condition and treatment protocol requirements.

The International Association for the Study of Pain (IASP) has defined pain as "an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage" (Bonica, 1979). Children can report pain due to both actual or potential connective tissue disruption and anticipatory distress during cancer treatment–related procedures (Jay, Elliott, Ozolins, Olson, & Pruitt, 1985). Owing to their limited cognitive and affective development status, children tend to rely on parent caring to somewhat buffer their pain and distress during invasive procedures (Blount et al., 1989; Caldwell-Andrews, Blount, Mayes, & Kain, 2005). Throughout this document, the term "during an invasive procedure(s)" is used to connote the process of anticipating, undergoing, and recovering from the invasive procedure. Thus, parents play essential and important roles in physically and emotionally caring for their child throughout the trajectory of cancer treatment–related procedures. Children with cancer could experience higher levels of procedure-related pain and distress if their parents also experience procedure-related distress and thus are less able to care for the child during an invasive procedure.

Treatment-related procedures can negatively impact children with cancer and their parents. Children reported that treatment-related procedures can be more traumatic than cancer itself (Ljungman, Gordh, Sorensen, & Kreuger, 1999; Miser, McCalla, Dothage, Wesley, & Miser, 1987). They experienced cooccurring symptoms related to these procedures such as pain, fatigue, and distress (Gedaly-Duff, Lee, Nail, Nicholson, & Johnson, 2006; Hedstrom, Haglund, Skolin, & von Essen, 2003; Kestler & LoBiondo-Wood, 2012; Poder, Ljungman, & von Essen,

2010). As an example, 30% of children with cancer reported moderate to severe pain as a direct or indirect effect of cancer−related therapies or treatment−related procedures (Jacob, Hesselgrave, Sambuco, & Hockenberry, 2007; Ljungman, Gordh, Sorensen, & Kreuger, 1999; Ruggiero et al., 2007). Unrelieved pain can cause more pain-related time in bed and sleep disturbances for children with cancer (Ljungman et al., 1999), which can significantly decrease children's quality of life (Miller, Jacob, & Hockenberry, 2011). In addition, memories of procedure-related pain and distress can make the anticipation of subsequent treatment−related procedures more difficult (Frank, Blount, Smith, Manimala, & Martin, 1995) and can have negative consequences for childhood cancer survivors such as avoidance of regular primary and long-term follow-up care (Davies, Butler, & Goldstein, 1972; Pate, Blount, Cohen, & Smith, 1996). Moreover, experiencing their child's treatment−related procedures has been associated with the development of anxiety and post-traumatic stress symptoms (PTSS) in parents of children with cancer (Harper et al., 2014; Kazak, Penati, Waibel, & Blackall, 1996a).

Owing to the detrimental effects of treatment-related procedures, clinical practice has significantly changed to improve the impressions they leave on children with cancer and their parents. In particular, conscious sedation or general anesthesia is applied prior to LPs and BMAs, especially when multiple procedures will be performed; topical anesthetics are also applied to the site of port start (Pizzo & Poplack, 2010). Nevertheless, children still express pain and distress during the port starts when they see the needle advancing toward their chest and feel pressure as the needle is inserted. These sensations are both frightening and heralding the start of a treatment cycle during which they can expect to experience multiple symptoms. Compared with LPs and BMAs, port starts have not been amply explored as providing opportunities for improving the cancer experience for children and their parents. Therefore, research is needed to identify parent

behavioral and emotional responses and parent-child interactions that contribute to child pain, distress, and cooperation during port starts and potentially in the long run. To improve the port start experience for children with cancer, research that examines child factors, parent factors, parent-child interactions, and child outcomes of port starts is needed.

Literature Review

Child Factors and Invasive Procedures

Child-related factors have been shown to predict child's experience with invasive procedures. Previous studies indicated that child temperament (e.g., distractibility and, conversely, persistence) could partially account for their pain and distress during painful procedures (Broom, Rehwaldt, & Fogg, 1998; Helgadottir & Wilson, 2004; Schechter, Bernstein, Beck, Hart, & Scherzer, 1991). Also, Chen and colleagues (2000) found that child pain sensitivity measured by the self-report Sensitivity Temperament Inventory of Pain was significantly associated with their pain and distress both in anticipation of and during LPs, indicating that a higher level of pain sensitivity is significantly associated with higher pain and anxiety levels. Chen et al. (2000) also found that younger children reported higher procedural distress and pain, and girls reported more pain than boys during LPs. However, the impact of these child-related factors on a child's experience is rarely explored for children in the context of cancer treatment–related port starts.

Parent Factors and Invasive Procedures

Parent-related factors can affect the child's coping responses to painful stressors. Studies have found that increased distress in parents with high levels of catastrophizing thoughts could lead to increased engagement in pain-attending behaviors post LPs and BMAs, as well as more pain, distress, and pain behavior for children with cancer (Caes, Vervoort, Devos, Verlooy,

Benoit, & Goubert, 2014). Studies that have examined parent distress and parent pain-attending behaviors in relation to port starts are rare. Additionally, the moderating effect of parent demographic factors (i.e., age, race, education, and prior experiences with distressing procedures) on the relationships between parent behaviors and child treatment responses are also under-explored in relation to port starts. Parents can play important roles in the provision of physical and emotional support to their child throughout the cancer treatment trajectory, including around the time of treatment procedures. Children with cancer could suffer more pain and distress if their parents are less able to provide this care due to parent coping behaviors.

Parent-Child Interactions and Invasive Procedures

Parent presence during invasive procedures has been widely studied with the conclusion that a shift should be made from studying the mere influence of parent presence to understanding parent-child behavioral interactions during procedures (Caldwell-Andrews, Blount, Mayes, & Kain, 2005; Chorney, Tan, & Kain, 2013). For children being treated for cancer, parent behaviors can interactively impact child pain and distress in relation to invasive procedures. Frank and colleagues (1995) found that mother behaviors could account for 53% of the variance in child distress during immunizations. Blount et al. (1989) investigated parent-child interactions during LPs and BMAs and found that parent coping-promoting behaviors (referring to behaviors that can promote child's coping), including humor, commands to use coping strategies, and nonprocedural talk, can reduce child distress and increase child coping levels (Blount, Bunke, Cohen, & Forbes, 2001). In contrast, parent distress-promoting behaviors (referring to behaviors that can promote child's distress), including verbalization of empathy, criticism, apology, giving control to the child, and reassurance, can promote child distress during LPs and BMAs (Blount et

al., 1989, 2001). The same might be true for children in the context of cancer treatment–related port starts.

Among distress-promoting parent verbal behaviors, reassurance and empathy have been identified as being the primary parent vocalizations toward their child during invasive procedures (Cohen, Manimala, & Blount, 2000). However, previous studies reported mixed findings for both of these parent verbal behaviors. First, Cline and colleagues (2006) found that more parental verbalizations of empathy and reassurance were associated with less pain and distress during port starts. Additionally, McMurtry and colleagues (2006, 2007) proposed that reassurance is a complex concept with sub-concepts that could cause contradictory outcomes in children undergoing immunizations. Likewise, Penner et al. (2008) re-conceptualized parent empathy comments into two categories (i.e., empathy concern and empathy distress) and found that parent empathy concerns had negative correlations with child's distress and parental empathy distress showed positive correlations with child's distress during port starts in children with cancer.

Consequently, investigations should be undertaken to clarify these mixed findings about parent-child interaction behaviors during port starts. Several directions can be considered. First, due to lack of consistency for the definitions of parent communication behaviors, studies are needed to clarify these verbal behaviors within future behavioral coding measures and then reexamined to see if and how parent behaviors can affect child pain, distress, and cooperation during invasive procedures such as the port starts. Second, although other researchers have studied parent verbal behaviors, parent nonverbal behaviors are less explored, particularly in the childhood cancer context. Both verbal and nonverbal behaviors should be conceptualized as a whole within parent-child interactions in future studies. Last, different observational coding systems have been used to quantify parent-child interaction behaviors during invasive

procedures, which might be attributed to the mixed findings of previous studies. A systematic evaluation of these widely used coding systems of parent-child interaction could potentially explain these mixed findings.

Observational Measures of Parent-Child Interactions During Painful Procedures

The importance of parent-child interactions during invasive procedures arises from findings of strong relationships between parental behaviors and child coping behaviors in previous studies. As previously mentioned, child's pain and distress showed negative correlations with parental coping-promoting behaviors and positive correlations with parent distress-promoting behaviors (Blount et al., 1989, 2001). Clinical applications and research in this area require ways to accurately and reproducibly categorize parent-child interactions during invasive procedures. Use of different parent-child interaction coding systems could explain inconsistent findings in the literature on parent-child interaction studies. Thus, choosing a comprehensive and appropriate observational coding system is of great importance to study the influence of parent interaction behaviors on child's pain, distress, and cooperation during treatment-related procedures.

In general, three types of approaches have been used to measure and evaluate the process and outcomes of parent-child interactions during invasive procedures: pain and distress measures completed by child self-report, pain and distress measures completed on the child's behalf by one or more persons proximal to the child (i.e., parents and healthcare providers), and observational measures completed by trained coders or observers (Kazak, Penati, Waibel, & Blackall, 1996b). Each approach has advantages and disadvantages. Compared with child self-report and proximal-report measures, observational measures of parent-child interaction are more expensive and time-consuming in terms of the length of the training, data collection, and coding

processes (Bakeman & Gottman, 1997; Sharpe & Koperwas, 2003). However, appropriate use of these observational measures can generate valuable and objective data about children, parents, and healthcare providers in relation to invasive procedures (Blount et al., 1989; Cline et al., 2006). Until now, multiple observational coding systems have been developed and widely used in the parent-child interaction studies. Reliability and validity of these coding systems have been addressed as well.

Two types of observational coding systems, also referred to as interaction analysis systems (IASs), have been identified: "cure" systems that are meant to conduct measurements of instrumental behaviors (i.e., task-focused) and "care" systems that meant to conduct measurements of affective behaviors (i.e., emotion-based) (Bensing, 1991; Ong, De Haes, Hoos, & Lammes, 1995). In the context of parent-child interaction, these two systems reflect the child's need to know and understand (i.e., to cure) and child's need to feel known and understood (i.e., to be cared for). Parent cure behaviors, such as giving information, distraction, and mandating coping strategies, can be captured by available coding systems; parent care behaviors, such as empathy and touch, have been explored as well, but parent emotion is rarely studied including in the context of invasive treatment−related procedures for children with cancer. The pain and distress associated with invasive procedures cannot be relieved by either instrumental-based or affective-based parent behaviors. An observational coding system that attempts to capture both types of behaviors should be constructed in future studies, the ultimate goal being to intervene in parent coping behaviors during invasive procedures, which in turn can improve child treatment responses (i.e., less pain and distress but more cooperation).

Besides the definitive distinctions between "cure" and "care" coding systems, observational coding systems can be distinguished from each other with regard to several other

criteria: the population (i.e., to whom can the system be applied?), clinical relevance (i.e., is the system specifically designed for studying communication interaction during medical procedures?), observational strategy (i.e., is the coding done from video, audiotape, direct observation, or literal transcripts?), reliability and validity (i.e., has the system been shown to reliable and valid with regard to capturing the targeted behaviors?), and channels of communicative behavior (i.e., does the system have a plan for coding verbal behavior, nonverbal behavior, or both?) (Ong et al., 1995). Although the observational measures used in previous studies state clear operational definitions to promote validity of the conclusions about the study results, how to conceptualize aspects of parental behaviors such as reassurance and empathy is still unclear. Most coding systems were constructed based on clinical observations or in-depth literature review rather than theory. A systematic analysis of the available observational measures for coding parent-child interactions that specifically examines their strengths and limitations is essential to the development of theory-based observational measures for use in future research. The theory-based observational coding system can help understand and improve parent-child interactions during invasive procedures as a means to improving child pain, distress, and cooperation in the short term and potentially anticipatory pain and anxiety in the future.

The proposed dissertation research comprises three distinct studies in the area of parent-child interactions during painful procedures. The purpose of the first study (Chapter 2) is to systematically review and evaluate the extant observational coding systems that have been used to study parent-child interactions during painful procedures. The purpose of the second study (Chapter 3) is to develop a parent interaction coding system (i.e., the Parent Caring Response Scoring System [P-CaReSS]) informed by Swanson's Theory of Caring and conduct its preliminary psychometric evaluation. The purpose of the third study (Chapter 4) is to use the P-

CaReSS to examine the longitudinal change in parent interaction behaviors toward their child with cancer during port starts and relationships between parent interaction behaviors and parent distress, child distress and child cooperation over time.

Theoretical Framework

A theoretical framework can organize the study of parent interaction behaviors during treatment−related invasive procedures for a child by informing the development of a set of theoretically derived statements or operational definitions that can be used to categorize and provide insight into the behaviors. In terms of the "cure" and/or "care" features of parent-child interactions during invasive procedures, one of the caring theories seems a reasonable option to guide the study of parent interaction behaviors and child treatment-related responses. Among these caring theories is Swanson's Theory of Caring. Swanson (1991) conducted three phenomenological studies to inductively develop this theory and has defined caring as "a nurturing way of relating to a valued other person, towards whom one feels a personal sense of commitment and responsibility" (Swanson, 1991, p.165). Empirical interventions provide support for the use of Swanson's Theory of Caring to guide the development and testing of interventions that aim to improve patient care outcomes (Swanson, 1991, 1999; Swanson et al., 2009).

Swanson (1991) has defined five processes that comprise caring theory: 1) Knowing refers to "striving to understand an event as it has meaning in the life of the other person"; 2) Being with means "being emotionally present for the other person"; 3) Doing for means "doing for the other what he or she would do for him- or herself if it were at all possible"; 4) Enabling refers to "facilitating the other person's passage through life transitions and/or unfamiliar events"; and 5) Maintaining Belief means "sustaining faith in the capacity of others to get through events

or transitions and face a future with meaning" (Swanson, 1991). Swanson (1991, 1993) also defined subcategories for each caring process. Figure 1.1 presents this theory and the relationships between these five caring processes. Swanson (2013) has continued exploring relationships among these caring processes and suggested that these processes are interconnected with each other with the purpose of providing a holistic care environment for improving outcomes.

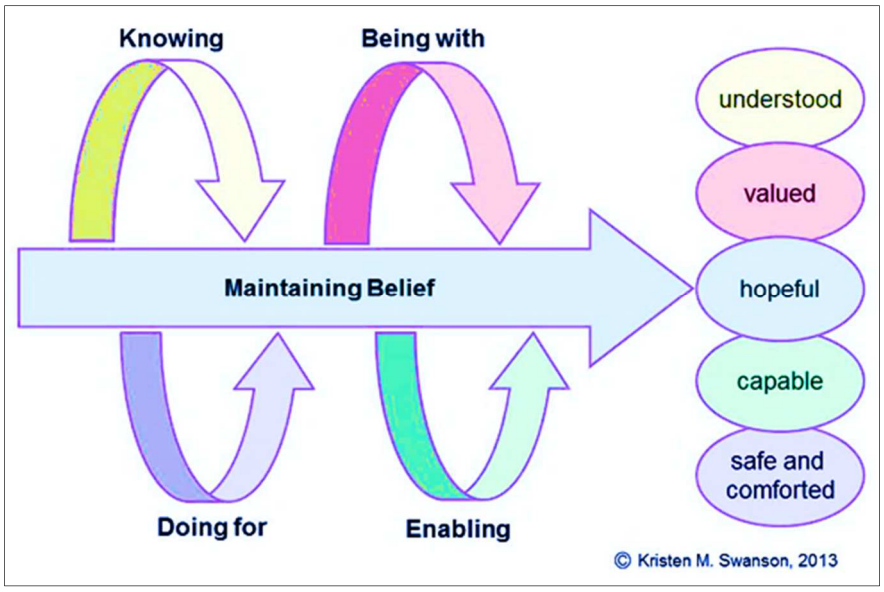

Figure 1.1. Swanson's Theory of Caring.

*Permission to use this image was obtained from Dr. Kristen Swanson

Why is Swanson's Theory of Caring appropriate for use in the parent-child interaction studies? First, the middle-range theory characteristics of this theory determine its potential use in parent-child interaction studies. Middle-range theories refer to a group of theories that has more limited scope and less abstraction, addresses specific phenomena or concepts, and also reflects meanings in practice (Im & Meleis, 1999; Maeve, 1994). This specific definition endorses that

middle-range theories (e.g., Swanson's Theory of Caring) are available to describe, understand, and explain specific phenomena or concepts that reflect and emerge from or focus on clinical practice such as parent-child interaction. A specific reason why this theory is selected is that parent interaction behaviors have a good fit with the five caring processes. For example, parent nonverbal behaviors (e.g., interpersonal distance and touch) echoed the domains of Being with and Doing for of Swanson's Theory of Caring; parent verbal behaviors (e.g., distraction talk and mandating coping strategies) can be conceptualized by the Doing for or Enabling domains of this theory. Thus, Swanson's Theory of Caring is suitable for use in parent-child interaction studies in terms of its middle-range theory characteristics and the conceptual congruence of parent behaviors with its five caring processes.

Second, Swanson's Theory of Caring has been developed and applied in studies with various populations, for example, parents and health professionals in social risk and critical care settings (Swanson, 1990, 1991, 1993); this bodes well for its applicability to other populations. Also, Swanson used nursing and non-nursing literature to develop her theory and gave a unique and generalizable description of the dynamics of the phenomena of a caring relationship (Kavanaugh et al., 2006; Swanson 1990, 1991, 1993). Given its history of having a diverse basis and applicability, Swanson's Theory of Caring is a reasonable theory to explore parent interaction behaviors toward their child during invasive procedures.

Last, previous studies have shown that the five caring processes can be used to improve patient outcomes (e.g., higher well-being, self-esteem, mood, and physical healing) and nurse outcomes (e.g., higher personal and professional well-being, self-efficacy, and job satisfaction) (Swanson, 1999; Tonges & Ray, 2011). Therefore, Swanson's Theory of Caring has potential for use in future studies that aim to develop and test interventions for improving child outcomes (i.e.,

pain, distress, and cooperation) by promoting parent interaction behaviors during invasive procedures such as port starts.

Impact and Innovation of the Proposed Research

Multiple observational measures have been developed for use in the parent-child interaction studies during invasive procedures. Evaluation of these existing measures is lacking and whether these measures account for all crucial behaviors is unknown. A systematic review and evaluation of the current observational measures of parent-child interactions is essential for improving the quality of future research (Chapter 2). The proposed review provided solid directions for the future study of these complex interactions and also provided clinicians with reliable and valid tools for use in care of children and parents.

In paper 2 (Chapter 3), Swanson's Theory of Caring informed the development of a new observational measure of parent interaction behaviors toward their child, i.e., the P-CaReSS. This new interaction coding system filled a gap—few observational measures of parent-child interactions are theory-based and include nonverbal behaviors. The use of an appropriate theory can help connect new knowledge with the previous knowledge by coherent and operational definitions. An observational coding system with clear theoretical foundations can be used as an important tool to guide evidence-based intervention programs. Moreover, Swanson's Theory of Caring has been used to inform the development of standardized questionnaires (Andershed & Olsson, 2009; Swanson, 2002); however, the current study extended its use in instrument development to the development of observational coding systems. Finally, this study provides an exemplar of how to develop an observational measure using a middle-range theory.

Paper 3 (Chapter 4) of this dissertation research provided additional evidence to revisit previous mixed findings regarding the influence of parent behaviors on child treatment responses

(i.e., distress and cooperation) during port starts. This study used a newer method (i.e., time-window sequential analysis). All the findings can help nurses and parents identify how to comfort their child during these procedures. In addition, findings of this study can advance parent roles in cancer treatment–related procedures and be used to assist healthcare providers and nurse educators in changing clinical practice policy related to nurse-operated procedures such as port starts. An adequate addressing of parent behaviors can potentially increase child's cooperation and thereafter increase nurse work efficiency and efficacy during the procedures.

Taken all together, this dissertation research has significant clinical implications for updating current healthcare policy and benefiting children with cancer, their parents, and clinicians in relation to treatment-related invasive procedures and possibly throughout the childhood cancer trajectory.

Outline of Dissertation

Chapter 2: Observational Measures of Parent-Child Interactions During Painful Procedures

Background

For the adult population, the IASs have been systematically reviewed to address physician-patient communications during painful procedures (Ong et al., 1995). For instance, several widely used IASs are identified as task-oriented coding systems (such as the Bales' Interaction Process Analysis [Bensing, 1991]) or as socio-emotional coding systems (such as the Patient-Centered Method [Henbest & Stewart, 1990]) or as both task-oriented and socio-emotional coding systems (such as the Roter Interaction Analysis System [Roter & Larson, 2002]). Similarly, multiple parent-child (or adult-child) IASs have been developed for use with children during a variety of painful procedures. However, the use of these parent-child IASs has

not been systematically reviewed; the categories of these IASs and the investigation of parent socio-emotional behaviors are still unknown among the pediatric population.

Purpose

The purpose of this paper was to systematically review and evaluate observational IASs that have been used to study parent-child (or adult-child) interactions during painful procedures.

Methods

Search strategies. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement (Moher, Liberati, Tetzlaff, Altman, & The PRISMA Group, 2009) informed the conduct and reporting of this systematic review (Figure 1.2). Several databases were searched for eligible studies, including PubMed, CINAHL, and PsycINFO, and Health and Psychosocial Instruments (HaPI). The databases were searched from their inception until December 2015. A string of search terms was developed as "(parent-child interaction OR adult-child interaction OR parent-child communication) AND (procedure*) AND (scale OR assessment OR measure OR coding)." Besides the searches using key terms, searches were conducted using the names of key researchers (i.e., Penner, L. A., Blount, R. L., and Caldwell-Andrews, A. A.).

Inclusion and exclusion criteria. All the studies included in this review reported the use of observational parent-child IASs during painful procedures. Specifically, eligible studies for this study had to meet the following criteria: 1) have the purpose of examining the reliability and/or validity or the use of parent-child IASs during painful procedures, 2) target the pediatric population (i.e., 0–18 years old), and 3) published in English journals. Studies were excluded if they were review or translated articles, or if they were not published in English, or if the full

texts were not available. The reference list of all included studies were reviewed to identify studies that the database searches might have missed.

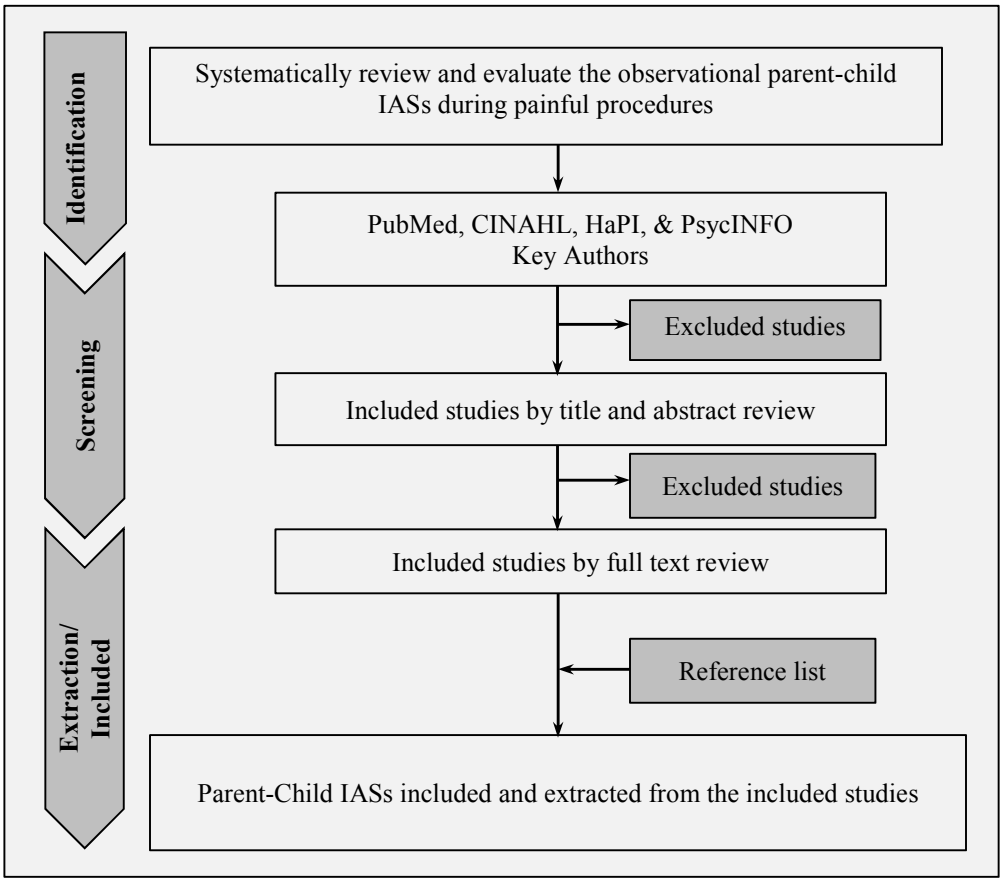

Figure 1.2. Flowchart of the study search, screening, and extraction process.

Data screening and extraction. The principal investigator (JB) searched all the databases to identify potentially eligible studies and scanned the identified studies first by title and abstract and then by the full text to assess their eligibility. A standard form was developed for data extraction in advance. For each included parent-child IAS, the extracted data included: study characteristics (i.e., authors, year of publication, name of the IAS, and study region), participant (i.e., child and parent) information (e.g., age, gender, ethnicity, diagnosis, or painful

procedures and sample size), and measures information—content (what does it measure?), clinical relevance (is it related to clinical practice?), observational strategies (e.g., audiotapes, videotapes, and direct observation), psychometric properties of IASs (i.e., inter- and intra-rater reliability and validity), channel of communicative behaviors (i.e., verbal behaviors, non-verbal behaviors, or both), and other strengths and weaknesses.

Evaluation criteria of the IASs. The criteria developed by the Society of Pediatric Psychology Assessment Task Force (SPP-ATF) were chosen to evaluate the observational systems for designing therapeutic interventions or broadening our understanding of the disease, the participants, and the studied phenomenon (Blount et al., 2008). According to the SPP-ATF criteria list, the observational parent-child IASs can be classified into three levels: well-developed assessment (to guide treatment or to broaden understanding), approaching well-developed assessment, and promising assessment (Table 1.1). Based on the criteria, all the included IASs were evaluated by the principal investigator (JB) in this study with their strengths and limitations specifically addressed.

Results

The study results were presented in tables and also in narrative form. Information to be presented in the tables included for each measure: demographic information, strengths and limitations of these identified IASs for use in children, and their levels based on the SPP-ATF criteria. Further recommendations for research and clinical applications of these measures were provided.

Implications

The findings provided a basis for determining appropriate use of the existing measures in future research and clinical care. The findings also informed the development of new

observational measures that aim to capture and describe the influence of parent behaviors on child outcomes during painful procedures.

Table 1.1. The Society of Pediatric Psychology Assessment Task Force (SPP-ATF) Criteria for Evaluating the Clinical Utility of Assessment Instruments

Measure Level		Specific Criteria
Well-established assessment that: (A) Guide treatment or (B) Broaden understanding	I	The measure must have been presented in at least two peer-reviewed articles by different investigators or investigatory teams.
	II	Sufficient detail about the measure to allow critical evaluation and replication (e.g., measure and manual provided or available upon request).
	III	Detailed (e.g., statistics presented) information indicating good validity and reliability in at least one peer-reviewed article.
		Scales classified as Well-established were further classified as:
		A Guide treatment: Results from the measure lead directly to the design of treatment interventions. Additionally, results from the measure may broaden understanding.
		B Broaden understanding: Results of measure broaden understanding of the participants, disease, or other aspect of the studied phenomenon.
Approaching well-established assessment	I	The measure must have been presented in at least two peer-reviewed articles, which might be by the same investigator or investigatory team.
	II	Sufficient detail about the measure to allow critical evaluation and replication (e.g., measure and manual provided or available upon request).
	III	Validity and reliability information either presented in vague terms (e.g., no statistics presented) or only moderate values (e.g., IRR coefficients and correlations with theoretically-based variables) presented.
Promising assessment	I	The measure must have been presented in at least one peer-reviewed article.
	II	Validity and reliability information either presented in vague terms (e.g., no statistics presented) or moderate values presented.
	III	Sufficient detail about the measure to allow critical evaluation and replication (e.g., measure and manual provided or available upon request).

Chapter 3: Developing and Testing a New Observational Coding System of Parent Interaction Behaviors

Background

Multiple observational IASs have been developed to capture parent-child (or adult-child) interacting behaviors during painful procedures such as the Child-Adult Medical Procedure Interaction Scale-Revised (CAMPIS-R) (Blount et al., 1997) and the CAMPIS-Short Form

(CAMPIS-SF) (Blount, Bunke, Cohen, & Forbes, 2001). However, most of these observational measures are not theory-based and emphasize more parent verbalizations rather than nonverbal behaviors, particularly the widely used CAMPIS, CAMPIS-R, and its derivatives (e.g., CAMPIS-SF). Recently, nonverbal behaviors have been included in observational measures but only for young children (i.e., the CAMPIS-Infant Version [CAMPIS-IV]) or when verbal communications are limited by the circumstances (i.e., the Perioperative-CAMPIS [P-CAMPIS]) (Blount, Devine, Cheng, Simons, & Hayutin, 2008). An observational measure that is informed by theory and considers both verbal and nonverbal behaviors is needed.

Purpose

The purposes of this study were: 1) to use Swanson's Theory of Caring to inform the development of an observational measure of parent interaction behaviors (i.e., P-CaReSS) and 2) to conduct preliminary psychometric evaluation of the new observational measure.

Methods

Sample. This study used two extant sources of data: a publicly available documentary film and both video-recordings and questionnaire data from a primary study of children with cancer (Title: Resources, parent-child communication and adjustment to pediatric cancer, RO1CA138981; PI: L. Penner). First, six video clips showing parents' interactions with their daughter as she underwent venipuncture during her visit to an Emergency Room were extracted from the documentary "The Waiting Room" (Nicks, 2012). Together, the video clips were about 15 minutes in duration. The video clips were used to inductively generate preliminary observational codes for the new observational measure (i.e., P-CaReSS) (Figure 1.3 S_1). Parent behavioral codes were generated every 20 seconds. Then these parent behavioral codes were deductively structured into domains consistent with the five caring processes of Swanson's

Theory of Caring. These codes formed the basis of the P-CaReSS (Figure 3 S_2). Second, a subset of 29 children receiving repeated port starts was used to refine this new observational measure and test its inter-rater reliability (IRR) and validity (Figure 1.3 S_3).

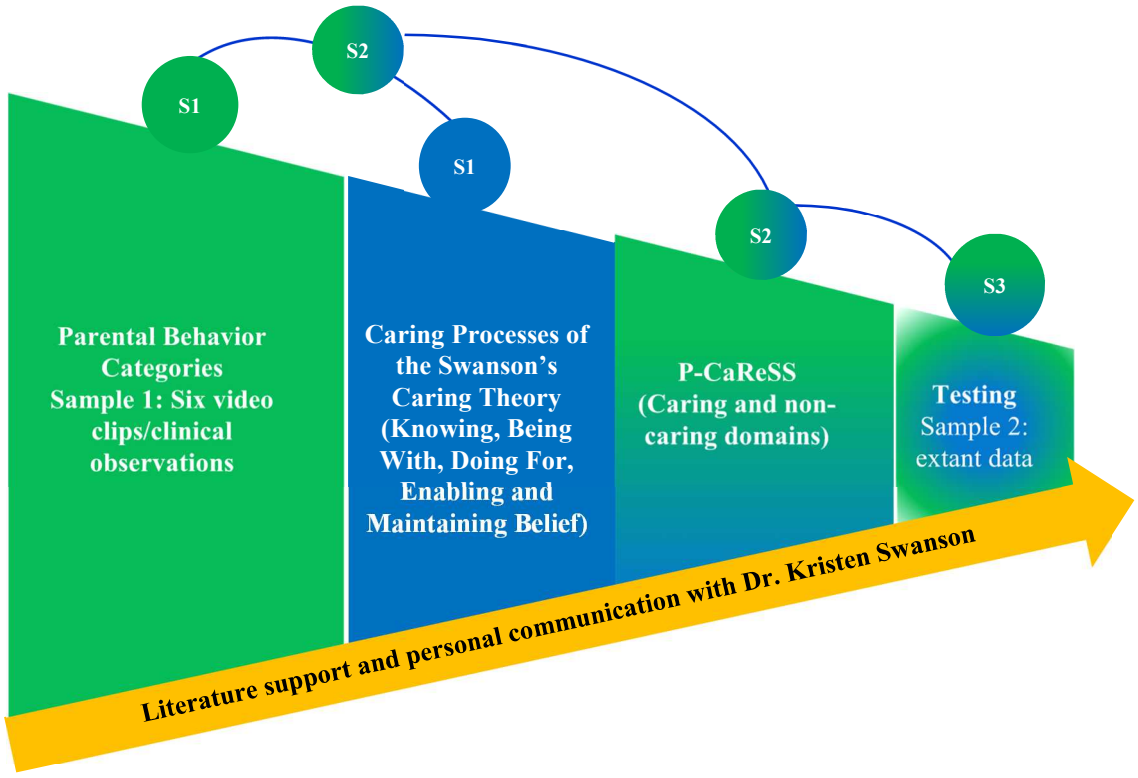

Figure 1.3. The development process of the P-CaReSS.
S_1: Parental behaviors are inductively identified from six video clips; the caring domains of the Swanson's Theory of Caring are reflected; S_2: Parental behaviors identified in S_1 are deductively constructed based on Swanson's Theory of Caring, resulting in the Caring and Non-caring domains of the P-CaReSS; S_3: Further testing of the P-CaReSS by an extant dataset. Through all the S_1-S_3, previous literature and personal communication with Dr. Kristen Swanson are continuously used to support the development process of the P-CaReSS.
Note: P-CaReSS = Parental Caring Response Scoring System; S_1 = Step 1; S_2 = Step 2; S_3 = Step 3

Development of the P-CaReSS. The P-CaReSS is comprised of mutually exclusive and exhaustive behavioral codes that had simple characteristics (Bakeman & Gottman, 1997; Sharpe & Koperwas, 2003). The five-step procedure described by Backman and Gottman (1997) was used to develop the P-CaReSS. These five steps were: 1) defining the purpose of developing the

new observational measure (i.e., to assess parent behavioral interactions toward their child during invasive procedures); 2) deciding the feature of the codes (i.e., social-based codes rather than physical-based codes); 3) formulating the initial P-CaReSS, 4) constructing operational definitions that meet the following criteria: objectivity, clarity and completeness; and 5) refining the P-CaReSS (Sharpe & Koperwas, 2003). The new tool was tested as follows: 1) training coders to use the tool reliably, with retraining indicated if the observer(s) indicated unacceptable IRR (i.e., Cohen's kappa < 0.70); and 2) testing its preliminary psychometric properties using the extant videos recordings of children during port starts.

Reliability and validity. A random selection of between 10% and 30% sample of the possible sessions is adequate to examine the IRR by more than one observer (Ostrov & Hart, 2013). Thus, video data from 11 of 83 children (13%) in the primary study was randomly chosen to estimate the IRR using Cohen's kappa coefficient (Bakeman & Gottman, 1997; Ostrov & Hart, 2013; Sharpe & Koperwas, 2003). Bakeman and Gottman (1987) suggested that kappa values less than 0.70 are worrisome. Validity of the P-CaReSS was examined by estimating correlations between P-CaReSS domains and ratings of indicators of theoretically-related variables (e.g., parent distress, child distress, child cooperation by multiple raters.

Implications

The development of the P-CaReSS was informed by Swanson's Theory of Caring and included both verbal and nonverbal parent interaction behaviors during port starts. The P-CaReSS provided a new tool to help researchers and clinicians assess and describe parent behaviors during painful procedures. The tool can also be used to evaluate the efficacy of interventions that aim to increase parent interaction behaviors during childhood cancer treatment–related procedures.

Chapter 4: Relationships Between Parent Interaction Behaviors and Child Treatment Responses

Background

Port start is a regular procedure for children receiving cancer treatment and is normally carried out by nurses in the presence of parents. Studying parent interaction behaviors during port starts can be a means for understanding how nurses can care for parents so that they can in turn care for their child during this invasive procedure. Previous studies have provided explicit evidence regarding the importance of parent-child interaction behaviors during painful procedures. Most of these studies described parent interaction behaviors in a cross-sectional rather than in a longitudinal way; therefore, longitudinal change of parent interaction behaviors over time are less explored, especially during repeated port starts. Additionally, the majority of parent-child interaction studies use correlational analysis rather than a newer method: time-window sequential analysis (Chorney, Tan, & Kain, 2013). The strength of time-window sequential analysis is that it can be used to examine interactions that occur over time and the sequence of interaction behaviors. Moreover, previous studies have focused on parent verbal behaviors rather than parent nonverbal behaviors and study findings have been inconsistent, especially for parental distress-related verbalizations such as empathy and reassurance. In Study 2 (Chapter 3), an observational P-CaReSS was developed to address the limitations of previous observational measures. Thus, using the P-CaReSS, a longitudinal study of parent interaction behaviors during repeated port starts and the influence of these behaviors on child behavioral responses (e.g., child distress and child cooperation), would fill the gap regarding how parent interaction behaviors adjusted in response to child behaviors over trajectories of cancer-related port starts and, in turn, how parent interaction behaviors influence child behaviors over time.

Purpose

The purposes of this study were to: 1) examine changes over time in parent interaction behaviors and 2) investigate associations between parent interaction behaviors and parent distress, child distress and cooperation in the context of cancer treatment–related port starts.

Methods

Sample. This study was a secondary analysis of video and questionnaire data from the primary study (Resources, parent-child communication and adjustment to pediatric cancer; RO1CA138981; PI: L. Penner). Eligibility criteria for the primary study were: 1) child age between 3 and 12 years at study entry, 2) child currently in active cancer treatment, and 3) child scheduled to have a clinically indicated port starts, LPs, or BMAs. In the primary study, a total of 83 parent-child dyads were involved in at least one video-recorded treatment–related port start per dyad. To study parent interaction behaviors longitudinally, video and questionnaire data from 43 of the 83 parent-child dyads was subjected to secondary analysis; only these 43 dyads had 2-3 port starts that were included in the primary study.

Measures. Details about the study measures are displayed in Table 1.2. Parents completed self-report measures of parent and child demographic data form and trained coders coded parent interaction behaviors using the P-CaReSS. Child distress was assessed by Karmanos Child Coping and Distress System (Harper et al., unpublished data). Child pain and distress were assessed by the Wong-Baker Faces Scale (Wong & Baker, 1988). Child cooperation was measured by the Child Cooperation Scale (Peterson et al., 2014).

Coder training. Two coders coded the digital video data. With expert support from Drs. F. Harper and L. Penner, the principal investigator (PI) of the proposed study (JB) trained one research assistant (RA) to use the observational measures (i.e., the P-CaReSS and the K-CCD)

and StudioCode© software (StudioCode Business Group, Australia) to code the data. Five recorded videos presenting parent-child interaction during one port start per child were selected from the primary dataset to train the RA; these videos were not used in subsequent data analysis. Both coders coded the frequency of parent-child interaction behaviors and the onset-offset of these behaviors. The RA was considered reliable in assigning codes and credentialed to assign codes for use in data analysis when at least 80% of the RA and PI codes were in agreement or Cohen's κ value ≥ 0.80.

Table 1.2. Study Measures

Variable	Measure	Data Source	Time-point
Parent demographics	Gender, ethnicity, education, economic status	Parent	Baseline
Parent distress	Revised Wong-Baker Faces Scale (Wong & Baker, 1988)	Parent, nurse, observer	During*
Parent interaction behaviors	P-CaReSS (Bai et al., unpublished data)	Trained observer	Pre, during, post
Child demographics	Age, gender, time since the treatment, total number of procedures since diagnosis	Parent & medical chart	Baseline
Child behavioral distress	Karmanos Child Coping & Distress Coding System (Harper et al., unpublished data)	Trained observer	Pre, during, post
Child distress	Revised Wong-Baker Faces Scale (Wong & Baker, 1988)	Parent, nurse, child, observer	During*
Child cooperation	Child Cooperation Scale (Peterson et al., 2014)	Parent, nurse, observer	During*

Note: P-CaReSS = Parent Caring Responses Scoring System; Pre = pre-procedure; during = during the procedure; post = post-procedure

* Children reported the worst pain/distress and best cooperation during the whole procedure after completing the procedure

Data coding. Researchers have recently begun to code clinician-patient or parent-child interaction behaviors in brief temporal segments (or "thin slices") (Chorney, Tan, & Kain, 2013; Henry & Eggly, 2013) such as 5 minutes. In this study, three 5-minute slices (a total of 15 min) were selected and coded for the video-recorded procedure: 1) the first 5 minute before the port

start, 2) a 5-minute slice during the port start (i.e., when the child is distressed/not distressed), and 3) an additional 5-minute slice after the port start. Each coder (the PI and the RA) reviewed the selected video slices multiple times and then coded parent interaction behaviors once using the P-CaReSS.

Statistical analysis. Mean (standard deviation, SD) was used for the data with normal distribution and median (interquartile range, IQR) for the data without normal distributions. Number (percentage) was used to present the categorical data. Mixed modeling with the generalized estimating equation (GEE) method was used to investigate change in parent interaction behaviors over time, as well as the influence of parent interaction caring (vs. non-caring) behaviors on parent distress, child distress, and child cooperation. Finally, time-window sequential analysis—one type of time-event sequential analysis that asks whether the presence of a particular behavior (i.e., "given" code) increases or decreases the probability of occurrence of another behavior (I.e., "target" code) within a particular temporal window (e.g., 5 s)—was used to explore whether parent interaction behaviors can lead to less child distress and more child cooperation within a time period (i.e., 5 s) than parent interaction behaviors at any time. Use of the time-window sequential analysis was guided by the work of Chorney et al. (2010, 2013).

Implications

Findings of this study provided a basis for developing interventions that aim to support parents in caring for their child during port starts and to decrease the negative effects of invasive procedures on child and parent psychological health in the short and long term.

Human Subjects Considerations

Prior to the initiation of this dissertation research, ethical approval was obtained from the Protocol Review Committee (PRC), Karmanos Cancer Center, and then the Institutional Review

Boards (IRBs) at Wayne State University and The University of North Carolina at Chapel Hill. The PI verified with the producer that permission to use the documentary film "The Waiting Room" in the research is not required because the film is publicly online (Chapter 3). For the primary study, parents completed an informed consent form and signed a Health Insurance Portability and Accountability Act (HIPPA) release form; oral assent was obtained from children who were over the age of 3 years. To guarantee participants' privacy and confidentiality, all the demographic information, self-report, and video-recorded data were de-identified with a specific serial number assigned to each participant; the research team members and the trained coders took all due measures to protect participant privacy during video data coding process (Chapters 3 and 4). Only the trained coders and research team members can access the data. All data were stored in a password-protected computer. Both data coders received standard training and had adequate IRR coefficients when they started coding the video-recordings.

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CHAPTER 2. OBSERVATIONAL CODING SYSTEMS OF PARENT-CHILD INTERACTIONS DURING PAINFUL PROCEDURES: A SYSTEMATIC REVIEW

Introduction

Children undergo an array of painful procedures associated with the prevention or diagnosis and treatment of disease. These procedures commonly include heel sticks, immunizations, venipuncture, lumbar punctures (LPs), bone marrow aspirations (BMAs), port starts (i.e., accessing a venous access device referred to as a "port" that has been implanted under the skin and through which blood samples can be obtained and chemotherapies or supportive care agents can be delivered), and wound care-related procedures (Blount, Piira, Cohen, & Cheng, 2006; Czarnecki et al., 2011). Children report more suffering from these procedures than from the underlying disease or health problem (Finley & Schechter, 2003). Previous studies showed that inadequate management of painful procedures can lead to negative responses in children, including pain, distress, aggressive behavior, inability to concentrate, resistance to further procedures, and distrust of the healthcare team; these painful procedures can also cause long-term consequences in children and their families such as avoidance of regular primary cancer and condition-specific follow-up (Davies, Butler, & Goldstein, 1972; Pate, Blount, Cohen, & Smith, 1996). Therefore, as a first step toward developing strategies to better care for children and reduce negative responses to painful procedures, factors that can be modified to improve their experience during painful procedures should be addressed in practice and research.

A variety of factors can influence children's responses during painful procedures. McCarthy and Kleiber (2006) have built a model to understand the various types of factors that contribute to these responses. According to this model, child characteristics, parent characteristics and procedural variables play significant roles in explaining children's treatment-related responses. Importantly, this model also pinpointed that parent behaviors (e.g., distraction performance) can reduce children's pain and distress during painful procedures. With the emphasis on family-centered care by the Institute of Medicine (IOM) and other organizations (American Academy of Pediatrics, 2003; IOM, 2001; Institute for Patient- and Family-centered Care, 2012), a paradigm shift has occurred wherein understanding the nature, quality, and impacts of parent-child interactions during painful procedures takes precedence over merely documenting parent presence (Chorney, Tan, & Kain, 2013). Studies from Blount and colleagues (1989, 1992) have grouped parent-child interaction behaviors into three categories: coping-promoting, neutral, and distress-promoting behaviors. Recent studies further support conjectures that parent coping-promoting behaviors can reduce pain and distress, conversely, that parent distress-promoting behaviors can heighten their child's pain and distress (Chorney et al., 2013; Spagrud et al., 2008; Taylor, Sellick, & Greenwood, 2011). Taken together, these findings suggest that parent-child interaction behaviors matter a great deal in shaping children's responses during painful procedures.

Parent-child interaction is a complex phenomenon that requires specific and valid tools to capture and understand the various behaviors involved. The use of different observational or self-report tools might result in findings and conclusions that cannot be compared across studies to build the science. To our knowledge, multiple observational measures have been developed to assess parent-child interaction behaviors during painful procedures, however decisions about

which measure to use are challenging given the diverse conceptualizations and elements of parent-child interactions during painful procedures. Choosing a coding system that is reliable and valid and using it consistently across studies are fundamental to develop the science of how parent-child interactions can be improved to reduce children's pain and distress during painful procedures. A critical evaluation of how these parent-child interaction coding systems have been used can provide information about the strengths and limitations of extant measures that can both guide decisions about their use in practice and research and direct the development of new tools to address identified limitations and gaps. Thus, the purpose of this study was to systematically review and evaluate extant observational coding systems of parent-child interactions during painful procedures.

Methods

This study used the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines, which include four components: identification, screening, eligibility, and included (Moher, Liberati, Tetzlaff, Altman, & The PRISMA Group, 2009).

Search Strategies

Five electronic databases were searched for eligible research studies, including PubMed, Cumulative Index to Nursing and Allied Health Literature (CINAHL), PsycINFO, Web of Science, and Health and Psychosocial Instruments (HaPI). All these databases were searched from their inception to January 2015. A string of search terms was developed such as "(parent-child interaction OR adult-child interaction OR parent-child communication) AND (procedure*) AND (scale OR assessment OR measure OR coding)." In addition to searching by key words, reports published by three key parent-child interaction researchers (i.e., Blount, R. L., Caldwell-Andrews, A. A, and Penner, L. A.) were identified through PubMed and Web of Science (Table

2.1). All searching reports were filtered by language (English) and age (birth to 18 years). Eligible reports identified through the database search were screened by title and abstract first, and then potential eligible reports were screened further for eligibility by full text. Last, the reference lists of reports that meet eligibility criteria were reviewed to identify reports that eluded the database searches.

Table 2.1. Database Search by Key Words and Key Researchers

Database	Key Words	Key Researchers
PubMed	(Parent-child interaction OR adult-child interaction OR parent-child communication) AND (procedure*) AND (scale* OR assessment* OR measure* OR coding*)	Blount, R.L., Kain, Z.N., Penner, L.A.
Web of Science	NA	
CINAHL	(Parent-child OR adult-child) AND (interaction OR communication) AND (scale* OR assessment* OR measure* OR coding*)	NA
PsycINFO		
HaPI		

Note: CINAHL = Cumulative Index to Nursing and Allied Health Literature; HaPI = Health and Psychosocial Instruments; NA = Not Applicable

Inclusion and Exclusion Criteria

To be eligible for inclusion in this review, reports were required to: 1) examine the reliability and/or validity or use of observational coding systems of parent-child interaction, 2) focus on parent-child interactions in the context of one or more painful procedures, 3) target children (ages 0–18 years), and 4) be published in an English-language journal. Excluded from this review were reports that presented the results of literature reviews, articles translated into English from another language, reports about coding systems of parent-child (adult-child) interactions that did not involve observational methods, and referenced reports that had not been published.

Data Extraction

Data were extracted from eligible studies using a standard form, including study characteristics (author, year of publication, name of the measure, and study location), participant information (age, gender, ethnicity, diagnosis or painful procedures, and sample size), and measure information (content [what does it measure?], clinical relevance [is it related to clinical practice?], observational strategies [audiotapes, videotapes, and direct observation], psychometric properties of pain scales [reliability and validity], communication channels [verbal or nonverbal behaviors, or both], and other relevant strengths and weaknesses). Detailed information of the data extraction form can be obtained from the author on request. The first author (BJ) and one trained research assistant (RA) completed the data extraction and comparisons. All the discrepancies of data abstraction between the two data extractors were resolved by face-to-face discussions.

Coding System Evaluation

Until now, no standard criteria are available for evaluating observational coding systems of parent-child interactions. In this study, the criteria from the Society of Pediatric Psychology Assessment Task Force (SPP-ATF) were chosen to evaluate the identified observational coding systems (Blount et al., 2008). These criteria were originally developed for the purpose of evaluating therapeutic interventions and/or broaden our understanding of specific participants, diseases, and phenomena under study. These criteria were built with important components such as reliability and validity, which are described as essentials in the Standards for Educational and Psychological Testing (American Educational Research Association, American Psychological Association, & National Council on Measurement in Education, 1999). Therefore, these components in the SPP-ATF are applicable for the evaluation of observational coding systems of

parent-child interactions. The first author (BJ) used these criteria to evaluate the observational coding systems in the eligible studies by assigning each system to one of three categories (i.e., well-established, approaching well-established, and promising) according to three levels within that category (Table 2.2). The identified coding systems were also evaluated by the following criteria, including theoretical basis, communication channels, and targeted population.

Table 2.2. The Society of Pediatric Psychology Assessment Task Force (APP-ATF) Criteria

Category	Level	Definition
Well-established assessment	I	The measure has been presented in at least two peer-reviewed articles by different investigators or investigatory teams;
	II	Sufficient detail about the measure to allow critical evaluation and replication (e.g., measure and manual provided or available upon request);
	III	Detailed information (e.g., statistics) indicating good validity and reliability in at least one peer-reviewed article;
Approaching well-established assessment	I	The measure has been presented in at least two peer-reviewed articles, which might be by the same investigator or investigatory team;
	II	Sufficient detail about the measure to allow critical evaluation and replication (e.g., measure and manual provided or available upon request);
	III	Validity and reliability information either presented in vague terms (e.g., no statistics) or only moderate values (e.g., IRR coefficients and correlations with theoretically-based variables) presented;
Promising assessment	I	The measure has been presented in at least one peer-reviewed article;
	II	Sufficient detail about the measure to allow critical evaluation and replication (e.g., measure and manual provided or available upon request);
	III	Validity and reliability information either presented in vague terms (e.g., no statistics) or moderate values presented;

Results

Study Characteristics

Figure 2.1 shows the flow of information into this study as required by the PRISMA guidelines (Moher et al., 2009). A total of 3380 reports were originally identified by databases searches. Ultimately, 16 studies were deemed eligible for inclusion in this review. The majority of these studies were published between 1990 and 2010 (10/16; 62.5%), reported on research

conducted in the United States (15/16; 93.8%), focused on children age 3–12 years (11/16; 68.8%), and involved sample sizes of fewer than 50 children (7/16; 43.8%). Detail information for the eligible studies and study participants is shown in Table 2.3.

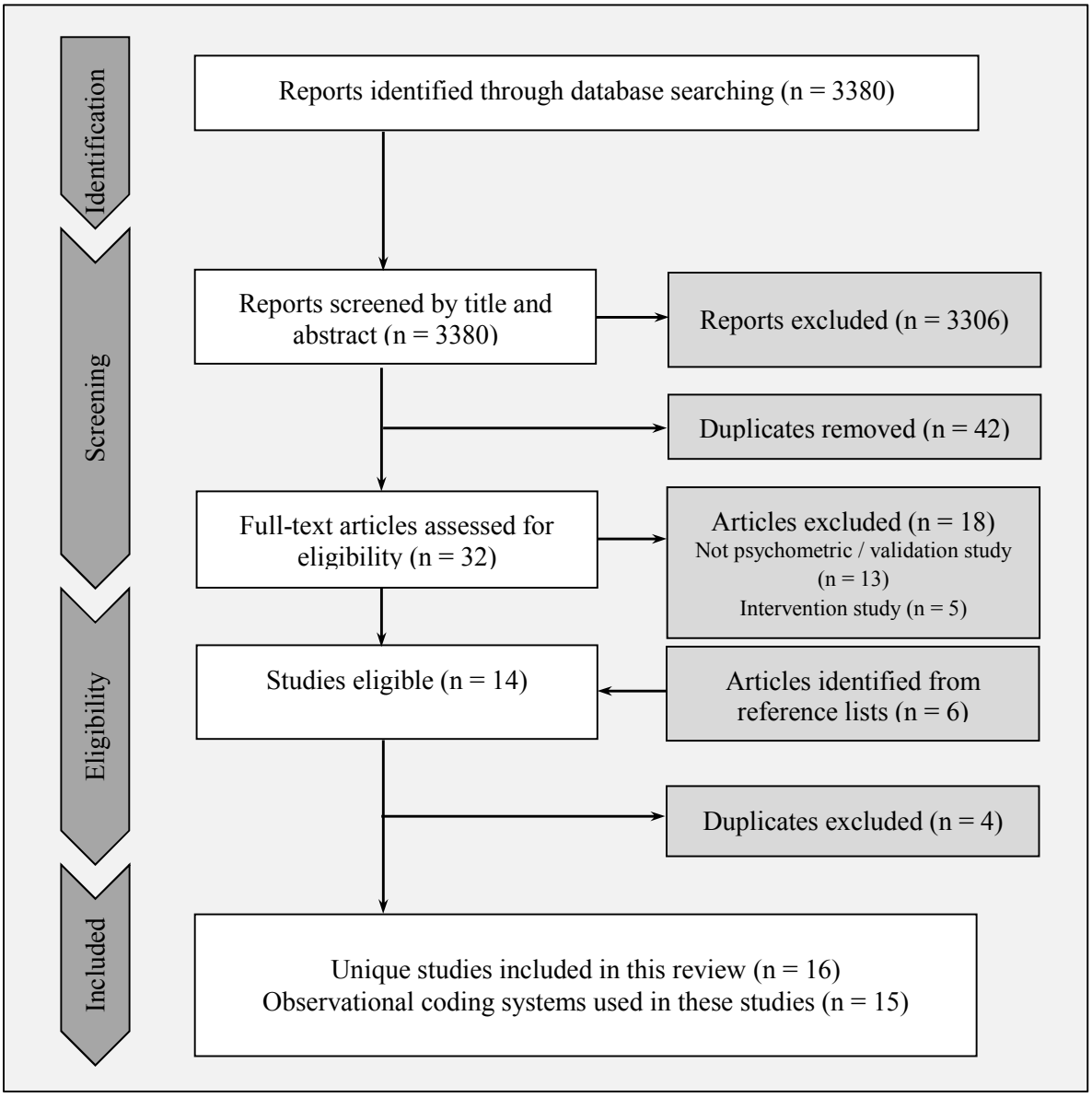

Figure 2.1. Flow diagram in the study.

Characteristics of the Coding Systems

A total of 15 observational coding systems of parent-child interactions were used in the eligible studies. The majority of these coding systems (13/15; 86.7%) have no theoretical basis. The majority of the measures were developed for use in both children and parents (10/15; 67%), included verbal and nonverbal behaviors (11/15; 73%), and used video recordings as the observational strategy and basis for coding (10/15; 67%). Detailed characteristics regarding these coding systems are shown in Table 2.4.

Evaluation of the Specific Coding Systems

Three of the 15 observational coding systems were developed to capture child behaviors during painful procedures, including the Observational Scale of Behavioral Distress (OSBD) (Jay, Ozolins, Elliott, & Caldwell, 1983), Behavioral Approach-Avoidance and Distress Scale (BAADS) (Bachanas & Blount, 1996; Hubert, Jay, Saltoun, & Hayes, 1988), and Child Behavior Coding System-Post Anesthesia Care Unit (CBCS-P) (Chorney, Tan, Martin, Fortier, & Kain, 2012). Meanwhile, Parent Communication Typology (Cline et al., 2006) and Interpersonal Distance and Touch Coding System (Peterson et al., 2007) were the two coding systems intended to assess parent behaviors during cancer-related procedures; both of these coding systems were also the only systems with clear theoretical foundations.

Six of the other 10 coding systems were regarded as modifications of the Child-Adult Medical Procedure Interaction Scale (CAMPIS) (Blount et al., 1989) for use in different clinical situations or specific age groups, including the CAMPIS-Revised (CAMPIS-R) (Blount et al., 1997), CAMPIS-Short Form (CAMPIS-SF) (Blount, Bunke, Cohen, & Forbes, 2001), Perioperative CAMPIS (P-CAMPIS) (Caldwell-Andrews, Blount, Mayes, & Kain, 2005), Modified CAMPIS-R (Walker et al., 2006), and CAMPIS-Infant Version (CAMPIS-IV) (Blount,

Devine, Cheng, Simons, & Hayutin, 2008). For the other four coding systems, two were specifically developed for use with infants: the Measure of Adult and Infant Soothing and Distress (MAISD) (Cohen, Bernard, McClellan, & Maclaren, 2005) and Generation R Infant Distress Scale (GRIDS) (Wolff et al., 2009). The remaining two coding systems were developed for use in specific situations: the Dyadic Prestressor Interaction Scale (DPIS) for pre-medical treatment situations (Bush, Melamed, Sheras, & Greenbaum, 1986) and Perioperative Adult Child Behavioral Interaction Scale (PACBIS) for perioperative settings (Sadhasivam et al., 2010). The matrix for the use of these measures is shown in Table 2.5.

Arranged chronologically, Table 2.6 describes the contents for each coding system and their strengths and limitations based on the literature and psychometric standards (Appendix 1).

Table 2.3. Participant Demographics in the Included Studies

Author, Year of Publication	Coding System	Child Age (Year) Mean (SD), Range	Child Sex (Boy/Girl)	Sample Size	Painful Procedures
Jay et al. (1983)	OSBD	2-20	26/16	42 children, 30 parents	BMAs
Bush et al. (1986)	DPIS	4-10	30/20	50 children, 50 mothers	Pre-medical treatments
Hubert et al. (1988)	BAADS	6.24, 3-11	26/17	43 children	Preparation for BMAs
Blount et al. (1989)	CAMPIS	9.8 (39 mos), 5-13	14/9	23 children, 23 parents	BMAs, LPs
Bachanas et al. (1996)	BAADS	5 (10 mos), 3-7	32/28	60 children, 55 mothers	Immunizations
Blount et al. (1997)	CAMPIS-R	6.2 (0.7), 4-7	36/41	77 children, 77 adults	Immunizations
Blount et al. (2001)	CAMPIS-SF	5 (10 mos), 3-7	32/28	60 children, 56 mothers, 4 female relatives, 1 father	Immunizations
Caldwell-Andrews et al. (2005)	P-CAMPIS	5.34 (2.5), 2-12	30/15	45 children, 45 parents	Induction of general anesthesia
Cohen et al. (2005)	MAISD	0.88 (0.37), 0.13-1.86	31/31	62 children, 62 parents	Immunizations
Cline et al. (2006)	Parent Communication Typology	3-12	18/13	31 children, 31 parents	Port starts, BMAs, LPs
Walker et al. (2006)	Modified CAMPIS-R	Child patients: 11.4 (2.11), 8-16; Healthy children: 11.23 (1.94), 8-15	NI	104 child patients, 119 healthy children 223 parents	Water load symptom provocation test
Peterson et al. (2007)	Interpersonal Distance and Touch Coding	3-12	17/12	29 children, 29 family members	Port starts, LPs
Blount et al. (2008)	CAMPIS-IV	8.7 mos (6.1mos), 2-21 mos	26/23	49 infants, 49 parents	Immunizations
Wolff et al. (2009)	GRIDS	1.2 (0.79), 13-18 mos	144/131	275 children, 275 parents	Venipuncture
Sadhasivam et al. (2010)	PACBIS	6 (median), 3-12	41/48	89 children, 89 parents	Perioperative period
Chorney et al. (2012)	CBCS-P	4.72 (2.24), 2-11	61/60	121 children, 121 parents	PACU recovery period

Note: BAADS = Behavioral Approach-Avoidance and Distress Scale; BMAs = bone marrow aspirations; CAMPIS = Child-Adult Medical Procedure Interaction Scale; CAMPIS-IV = CAMPIS-Infant version; CAMPIS-SF = CAMPIS-Short Form; CAMPIS-R = CAMPIS-Revised; CBCS-P = Child Behavior Coding System-Post Anesthesia Care Unit; DPIS = Dyadic Prestressor Interaction Scale; GRIDS = Generation R Infant Distress Scale; LPs = lumbar punctures; MAISD = Measure of Adult and Infant Soothing and Distress; mos = months; NI = no information; OSBD = Observational Scale of Behavioral Distress; PACBIS = Perioperative Adult Child Behavioral Interaction Scale; PACU = Post Anesthesia Care Unit; P-CAMPIS = Perioperative Child-Adult Medical Procedure Interaction Scale

Table 2.4. Characteristics of Observational Coding Systems of Parent-Child Interactions in the Included Studies

Author, Year of Publication	Coding System	Channels, Verbal Nonverbal or Both	Observational Strategy	Clinical Relevance	Theory Basis
Jay et al. (1983)	OSBD	Both	Direct observation	Yes	Previous measure
Bush et al. (1986)	DPIS	Both	Video recording	Yes	Literature and observation
Hubert et al. (1988)	BAADS	Both	Direct observation	Analog procedure	NI
Blount et al. (1989)	CAMPIS	Verbal	Audio recording	Yes	NI
Bachanas (1996)	BAADS	Both	Video recording	Yes	NI
Blount et al. (1997)	CAMPIS-R	Verbal	Video recording	Yes	NI
Blount et al. (2001)	CAMPIS-SF	Both	Video recording	Yes	NI
Caldwell-Andrews et al. (2005)	P-CAMPIS	Both	Video recording	Yes	NI
Cohen et al. (2005)	MAISD	Both	Video recording	Yes	NI
Walker et al. (2006)	Modified CAMPIS-R	Verbal	Audio recording	Water load symptom provocation test	NI
Cline et al. (2006)	Parent Communication Typology	Both	Video recording	Yes	Symbolic interactionism
Peterson et al. (2007)	Interpersonal Distance and Touch Coding	Nonverbal	Video recording	Yes	Hall's (1969) typology of interactional distances
Blount et al. (2008)	CAMPIS-IV	Both	Video recording	Yes	NI
Wolff et al. (2009)	GRIDS	Both	Video recording	Yes	Previous measure
Sadhasivam et al. (2010)	PACBIS	Both	Direct observation	Yes	Previous measure
Chorney et al. (2012)	CBCS-P	Both	Video recording	Yes	Previous measure

Note: BAADS = Behavioral Approach-Avoidance and Distress Scale; CAMPIS = Child-Adult Medical Procedure Interaction Scale; CAMPIS-IV = CAMPIS-Infant version; CAMPIS-SF = CAMPIS-Short Form; CAMPIS-R = CAMPIS-Revised; CBCS-P = Child Behavior Coding System-Post Anesthesia Care Unit; DPIS = Dyadic Prestressor Interaction Scale; GRIDS = Generation R Infant Distress Scale; MAISD = Measure of Adult and Infant Soothing and Distress; NI= none indicated; OSBD = Observational Scale of Behavioral Distress; PACBIS = Perioperative Adult Child Behavioral Interaction Scale; P-CAMPIS = Perioperative Child-Adult Medical Procedure Interaction Scale

Table 2.5. Use of Parent-Child Interaction Observational Coding Systems Based on Child Age, Pain Situations, and Target Population

Coding System	Child Age, Year	Pain Situation	Target Population
MAISD	< 3	Immunizations	Parents and children
CAMPIS-IV		Immunizations	
GRIDS		Venipuncture	
DPIS	3 - 12	Pre-medical treatment	
BAADS		Multiple procedures	Children
CAMPIS		Multiple procedures	Parents and children
CAMPIS-R		Multiple procedures	
CAMPIS-SF		Multiple procedures	
P-CAMPIS		Perioperative period	
Parent Communication Typology		Cancer treatment procedures	Parents
Interpersonal Distance and Touch Coding		Cancer treatment procedures	
PACBIS		Perioperative period	Parents and children
CBCS-P		Post Anesthesia Care Unit recovery period	Children
OSBD	2 - 20	Cancer treatment procedures	
Modified CAMPIS-R	> 12	Abdominal pain	Parents and children

Note: BAADS = Behavioral Approach-Avoidance and Distress Scale; CAMPIS = Child-Adult Medical Procedure Interaction Scale; CAMPIS-IV = CAMPIS-Infant version; CAMPIS-SF = CAMPIS-Short Form; CAMPIS-R = CAMPIS-Revised; CBCS-P = Child Behavior Coding System-Post Anesthesia Care Unit; DPIS = Dyadic Prestressor Interaction Scale; GRIDS = Generation R Infant Distress Scale; MAISD = Measure of Adult and Infant Soothing and Distress; OSBD = Observational Scale of Behavioral Distress; PACBIS = Perioperative Adult Child Behavioral Interaction Scale; P-CAMPIS = Perioperative Child-Adult Medical Procedure Interaction Scale

Multiple procedures indicate the combination of BMAs, venipuncture and other painful procedures

Table 2.6. Domains, Strengths, and Limitations for the Observational Coding Systems of Parent-Child Interactions

Coding System	Domain	Strength	Limitation
OSBD	•11 children verbal and nonverbal behaviors; •Each item weighted according to the intensity;	• Reliability by Pearson's r coefficient: 0.72-0.99 between 4 phases of procedure; • Agreement percentage: 0.80-0.91 between 4 study phases of procedure; • Children's OBSD significantly correlated with child anticipated pain and experienced pain, and parent-reported child anxiety;	• No theoretical support; • Child behaviors only; • Only focus on child distress but not child coping; • No real-time instrument directed intervention;
DPIS	•4 child behaviors: attachment, distress, exploration and prosocial; •6 parent behaviors: informing, distracting, reassuring, ignoring, restraining and agitation;	• Kappa values: 0.91-0.97 for child behaviors (0.77 for distress) and 0.92-0.99 for parent behaviors (0.60 for restraining); • Parent behaviors associated with adaptive and maladaptive child responses; • Sensitive to complex patterns of interaction involving more than one child and/or parent behaviors;	• Use prior to the medical procedures; • Limited to dyadic (mother-child) interactions; • Widely used in the Western countries;
BAADS	•2 subscales: approach-avoidance and distress with 10 items; •5-point globally anchored rating with a higher sum of these domains, indicating more approach and distress scores; •Every item was coded in five phases of procedures;	• Cronbach's α: approach-avoidance (0.78-0.82) and distress (0.78-0.95); • Cohen's kappa: approach-avoidance (0.65-0.78); distress (0.77-0.89); • Criterion validity: significant correlations with CAMPIS-R distress and coping, OSBD, parent/child-reported child fear and pain, and nurse-reported child distress and pain; • Construct validity: sensitive changes toward the coping skills interventions;	• No parent behaviors; • Without theoretical support; • Measure the coping quantity rather than the coping style and avoidance can be indicated as one way of distress; • Limited clinical implications in the development of therapeutic interventions based on this measure; • Widely used in North America in children of multiple ethnicities;
CAMPIS / CAMPIS-R	•35 codes (16 child vocalizations and 19 adult behaviors) •CAMPIS-R has six domains: child coping, child distress and child neutral Behaviors; parent and staff coping, distress promoting and neutral behavior; •Coding the existing	• Cohen's kappa values: CAMPIS (0.92 for child, 0.80 for adult, mean percentage agreement 89%); CAMPIS-R (0.72-0.91 for child, 0.65-0.92 for adults) • Predictive validity: child coping codes negatively correlated with OSBD and BAADS distress scores; child coping and child distress correlated with BAADS approach score in expected directions; • Concurrent validity: child coping scales negatively correlated with parent, child and staff-reported child fear and pain; child coping and child distress	• Long coding items; • Without theory support; • No information of the motoric behaviors (e.g., touch, proximity, eye contact); • CAMPIS-R subscales may not be as relevant or reliable for use in UK samples and samples from other countries; • Widely used in Western countries;

	frequency of behaviors;	scales correlated in the expected directions with parent-reported ability to help their children and with staff-reported child cooperation; • Sensitive changes of therapeutic intervention effects based on the CAMPIS-R subscales; • Clinical implication related to its direct use to design therapeutic interventions;	
CAMPIS-SF	•6 items**:** child coping, child distress; parent coping promoting, parent distress promoting; staff coping promoting and staff distress promoting; •5-point rating anchors used from none or one (1) to maximum or nearly continuous (5); •Sum score was used;	• Cohen's kappa values: 0.88-0.90 for child, 0.82-0.92 for parent, 0.92-1.0 nurses; • Convergent validity: ratings for the different CAMPIS-SF factors correlated in the expected directions with CAMPIS-R and BAADS measures, and with nurse report, parent report child self-report measures; • Construct validity: nurse behavior was correlated with child coping and parent behavior correlated with child distress during therapeutic interventions; • Economy to use with short items;	• Limited validity information; • Too much information loss; • Without theoretical support; • Limited use in American studies; • Low sensitivity: no change in child behavior after the coping skills intervention; • Lack of implications in studies;
P-CAMPIS	•40 codes grouped into verbal and nonverbal interactions between children, parents, and medical personnel; •Adult-adult communication (5 codes); adult-child communication (18 codes); child vocalizations (9 codes); nonverbal behavior (7 codes); either adult–adult interactions or adult-child interactions (1 code);	• Cohen's kappa values: averaged 0.87 for adult verbal codes, 0.92 for child verbal codes and 0.88 for nonverbal codes; • Convergent validity: children who verbalized resistance, fear, or crying in the P-CAMPIS indicated significantly more anxiety during induction of anesthesia;	• Without theoretical support; • Low sensitivity: no change in child behavior after the coping skills intervention; • Limited for use in the Western countries and in the perioperative environments; • No postoperative child and parent behaviors; • No real-time instrument directed interventions;
MAISD	•11 parent and 6 nurse verbal and nonverbal behaviors; •9 infant behaviors;	• Cohen's kappa values: 0.66-1.0; • Concurrent validity: MAISD infant distress associated with nurse-reported infant VAS pain scores (r = 0.27) and parent-reported infant pain (r = 0.32); MAISD scores of infant distress associated with infant distress scores measured by the Modified Behavior Pain Scale (r = 0.44);	• Limited external validity for use in infants and in other procedures; • No theoretical support and all the codes from literature and clinical observation; • Not comprehensive in identifying adult behaviors that influence infant distress; • Not examine specific body positions, such as holding the infant belly-to-belly or in a kangaroo care position;

Parent Communication Typology	• Four communication patterns: normalizing, invalidating, supportive and distancing; • Each pattern was coded as presence or absence;	• Cohen's kappa value of 0.81 and 89.5% agreement between two coders; • Intra-rater reliability with 100% agreement; • Developed based on the symbolic interactionism framework; • Showing the resemblance to the attachment styles; • Including verbal and nonverbal behaviors;	• With limited validity information; • Lack of clinical therapeutic effects from interventions based on this measure; • Not for healthcare provider's behaviors; • Only used in Western countries;
Modified CAMPIS-R	• Parental verbal attending talk: any talk by the parent about the child's symptoms; • Parental distracting talk: any talk by parents that did not focus on the child's physical sensations or the procedure; • Uncodeable Talk; • Children's utterance: symptom complaints and other talk;	• Intra-class correlation coefficients: 0.95-0.99; • Divergent validity: compared with control group, children's symptom complaints nearly doubled in the parent attention group and reduced by half in the parent distraction group; • Easy to use with short coding items;	• Without theoretical support. • Without nonverbal coding for parents; • Limited for use in Western countries;
Interpersonal Distance and Touch Coding	• Interpersonal distance has 5 categories: intimate distance, personal distance, social distance, clinical distance and unknown; • Touch has 3 codes: instrumental touch, supportive touch, no touch and unknown; • All the codes were coded continuously in real time;	• Interpersonal distance was developed based on Hall's (1969) typology of interactional distances; • Average Cohen's kappa values: 0.80 for interpersonal distance and 0.75 for touch; • Average intra-rater reliability kappa values: 0.83 for interpersonal distance and 0.82 for touch.	• Only nonverbal behaviors for parents' behaviors; • Without theoretical support for touch; • Limited validity information; • Only used in North America;
CAMPIS-IV	• 5 adult motoric behaviors and nonprocedural talk to infant as coping promoting behaviors; • 7 adult vocal behaviors as distress-promoting behaviors; • Neutral behaviors;	• Cohen's kappa values: 0.82-0.97 for adult vocalizations, 0.91-0.99 for adult motoric behaviors, 0 .77-1.00 for child codes; • Including adult nonverbal behaviors;	• Without theoretical support; • Limited validity information; • Specific use in infants with limited external validity;

	• Two infant codes; • All behaviors were rated as occurring or not occurring;		
GRIDS	• 13 parent behaviors: verbal and nonverbal; • 14 child behaviors verbal and nonverbal; • Behaviors were coded as present or absent;	• Intra-class correlation coefficients: 0.65 -0.99; • Infant distress component positively associated with the nurses' visual analog scale rating of infant distress;	• Developed based on previous instrument; • No clear domains for this scale; • Limited external validity for use by other researchers;
PACBIS	• 4 dimensions of behavioral assessment: child coping, child distress, parent positive, and parent negative • Each dimension is scored 0, 1, or 2, with higher scores indicating increasingly maladaptive behaviors or psychological states;	• Cohen's kappa values: 0.62-0.82 for child coping, 0.83-0.94 for child distress, 0.66-0.73 for parental positive, 0.73-0.90 parental negative; • Child coping and child distress subscores of the PACBIS demonstrated strong concurrent correlations with the modified Yale Preoperative Anxiety Scale, CAMPIS-SF, and OSBD; • Parent positive subscore of the PACBIS strongly correlated with the CAMPIS-SF and OSBD; the parent negative subscore showed significant correlation with the Induction Compliance Checklist; • The PACBIS has strong construct (convergent and divergent) and predictive validities; • Having targeted instrument directed interventions; • Practical, simple and real time instrument;	• Only appropriate for the perioperative care period; • No theoretical support;
CBCS-P	• 23 verbal and nonverbal child behaviors that are combined into nonverbal distress, verbal distress, and non-distress behaviors; • Verbal and nonverbal parent behaviors;	• Cohen's kappa values: 0.60-1.00; • Concurrent validity: verbal distress composite score significantly correlated with FLACC (r = 0.24) and analgesic use (r = 0.28); nonverbal distress composite score with FLACC (r = 0.40) and analgesic use (r = 0.30); • Including verbal and nonverbal behaviors;	• Specifically use for children in post-anesthesia care settings; • No parent behaviors; • Without theoretical support for the codes; • Widely used in Western countries, such as Canada;

Note: BAADS = Behavioral Approach-Avoidance and Distress Scale; CAMPIS = Child-Adult Medical Procedure Interaction Scale; CAMPIS-IV = CAMPIS-Infant version; CAMPIS-SF = CAMPIS-Short Form; CAMPIS-R = CAMPIS-Revised; CBCS-P = Child Behavior Coding System-Post Anesthesia Care Unit; DPIS = Dyadic Prestressor Interaction Scale; GRIDS = Generation R Infant Distress Scale; MAISD = Measure of Adult and Infant Soothing and Distress; OSBD = Observational Scale of Behavioral Distress; PACBIS = Perioperative Adult Child Behavioral Interaction Scale; P-CAMPIS = Perioperative Child-Adult Medical Procedure Interaction Scale

Observational Scale of Behavioral Distress (OSBD). The OSBD was developed to assess child behavioral distress (Jay et al., 1983). It had good to excellent inter-rater reliability (IRR) ranging from 0.72 to 0.99. However, this scale focused on child distress but not child coping status, and no real-time interventions were developed based on the observational items of parent-child interactions in this measure.

Dyadic Pre-stressor Interaction Scale (DPIS). Bush and colleagues (1986) developed the DPIS to investigate mother and child interactions prior to BMAs. This coding system had acceptable to excellent IRR with kappa coefficients ranging from 0.77 to 0.97 for child behaviors and from 0.60 to 0.99 for maternal behaviors. This coding system was sensitive to complex patterns of child-parent interactions involving more than one child and/or parent behaviors. However, this coding system was developed to understand interactions between mother and child, so it might not be suitable for coding father-child interactions. Additionally, this system has been used to code parent-child interactions before painful procedures rather than throughout procedures. In addition, the definition of reassurance is confusing because the authors code verbal empathy, praise, and reassurance together as reassurance.

Behavioral Approach-Avoidance and Distress Scale (BAADS). The BAADS was designed to assess children's distress during painful procedures (Bachanas & Blount, 1996; Hubert et al., 1988). The BAADS showed excellent internal consistency for both the approach-avoidance subscale ($\alpha = 0.82$) and distress subscale ($\alpha = 0.95$). Its IRR ranged from acceptable ($\kappa = 0.65$) to very good ($\kappa = 0.89$). Construct validity of BAADS was supported by its sensitivity to change in a coping skills training study. However, this scale measured the quantity rather than the style of child coping and the use of avoidance coping can be viewed as a form of distress.

The potential for developing interventions based on the approach-avoidance subscale seems limited.

Child-Adult Medical Procedure Interaction Scale /CAMPIS-Revised (CAMPIS /CAMPIS-R). The CAMPIS /CAMPIS-R was developed to measure child and adult verbalizations during medical procedures (Blount et al., 1989, 1997). The IRR of this measure ranged from acceptable ($\kappa = 0.65$) to excellent ($\kappa = 0.92$) for all the behavioral codes. The primary strength of the CAMPIS /CAMPIS-R is that its six coding constructs can be used to guide interventions. However, the CAMPIS /CAMPIS-R was developed based on the literature without clear theoretical basis. The length of the 35 codes could compromise its use in clinical practice. Another significant limitation of this system is that it measures parent verbalizations without considering the impact of parental motoric behaviors such as touch and proximity on the child during painful procedures.

Child-Adult Medical Procedure Interaction Scale-Short Form (CAMPIS-SF). The CAMPIS-SF was adapted from the CAMPIS-R (Blount et al., 2001). The IRR of the CAMPIS-SF was from acceptable ($\kappa = 0.74$) to excellent ($\kappa = 0.92$). The CAMPIS-SF is easy to use in clinical practice and research. However, the items of the CAMPIS-SF were inherited from the CAMPIS-R without clear theoretical foundation. This scale showed low sensitivity to change in child behaviors after coping skills training interventions (Cohen, Bernard, Greco, & McClellan, 2002).

Perioperative Child-Adult Medical Procedure Interaction Scale (P-CAMPIS). The P-CAMPIS was adapted from the CAMPIS-R to measure adult-child interactions in the perioperative care settings (Caldwell-Andrews et al., 2005). Coders have been able to apply the scale with very good reliability; the average kappa values were 0.87 for adult verbal codes, 0.92

for child verbal codes, and 0.88 for nonverbal codes. This adaption was also developed without theoretical basis, has lengthy codes, and is only appropriate for use in the perioperative care environment.

Measure of Adult and Infant Soothing and Distress (MAISD). The MAISD was developed to code specific behaviors of nurses, parents, and infants during immunizations (Cohen et al., 2005). Raters have demonstrated acceptable to excellent IRR using the MAISD, with kappa coefficients ranging from 0.66 to 1.0 for parent, infant, and nurse behaviors. However, the MAISD was specifically developed for use in interactions with infants, therefore generalizability to interactions with older children is limited. The MAISD codes were derived from literature and clinical observations rather than theories. In addition, this scale did not examine the influence of specific body positions such as holding the infant belly-to-belly on infant distress level during immunizations, meaning that the influence of specific body positions on infants' levels of pain and distress should be cautiously interpreted.

Parent Communication Typology. Cline and colleagues (2006) developed this coding system to quantify parental communication behaviors to their child during cancer treatment–related procedures. This measure showed good IRR with an average agreement of 89.5% and kappa coefficient of 0.81. This scale was developed based on the symbolic interactionism framework but has not been widely used. Further evidence is needed to support the validity of this coding system and its application in research and practice is lacking. Moreover, assigning one type of communication to the entire procedure seems reductionistic given the complexity of parent-child interactions during painful cancer procedures.

Modified Version of CAMPIS-R. Walker and colleagues (2006) used a modified version of the CAMPIS-R to assess parent-child interactions during chronic abdominal pain

context in the child. This modified version of CAMPIS-R had excellent IRR with the intra-class coefficients (ICCs) ranging from 0.95 to 0.99 and is easy to use given its short length of codes. This measure could be used to guide interventions. However, this modification of the CAMPIS also lacks theoretical basis and does not consider the influence of parent nonverbal interaction behaviors on child during painful procedures.

Interpersonal Distance and Touch Coding. The Interpersonal Distance and Touch Coding System was developed to quantify parent interpersonal distance and touch during cancer treatment−related procedures for children (Peterson et al., 2007). The codes for personal distance were developed based on Hall's (1969) typology of interactional distances. This coding system had good IRR with average kappa coefficients of 0.80 for the interpersonal distance codes and 0.75 for the touch codes; it also shows good intra-rater reliability with average kappa coefficients of 0.83 for interpersonal distance codes and 0.82 for touch codes. Application of this coding system should be investigated in future intervention studies.

Child-Adult Medical Procedure Interaction Scale-Infant Version (CAMPIS-IV). The CAMPIS-IV was developed based on the CAMPIS-R to measure infant-adult interactions during painful procedures (Blount et al., 2008). Raters who use the CAMPIS-IV have shown acceptable to excellent IRR with kappa coefficients ranging from 0.77 to 1.00. The strength of this coding system lies in its brevity and inclusion of parental verbal and nonverbal behaviors during painful procedures. However, this scale also lacks a theoretical basis and support for its validity is in need of further development.

Generation R Infant Distress Scale (GRIDS). The GRIDS was developed to assess the infant-adult interactions during painful procedures (Wolff et al., 2009). Its intra-class coefficients

(ICCs) ranged from 0.65 to 0.99. However, this scale has no clear domains and limited support for generalizability.

Perioperative Adult Child Behavioral Interaction Scale (PACBIS). The PACBIS was developed to understand parent-child interactions in the perioperative period (Sadhasivam et al., 2010). This scale had variable IRR with kappa values ranging from 0.62 to 0.82 for child coping, from 0.83 to 0.94 for child distress, from 0.66 to 0.73 for parent positive, and from 0.73 to 0.90 for parent negative. This coding system is practical and simple to use and can direct interventions in real time. However, this system has no theoretical basis and is only suitable for use in the perioperative care period.

Child Behavior Coding System-Post Anesthesia Care Unit (CBCS-P). The CBCS-P was developed to measure children's distress and non-distress behaviors in the post-anesthesia care unit (PACU, Chorney et al., 2012). The IRR of the CBCS-P ranges from kappa values of 0.57 to 1.0. However, it was specifically developed for use in children in the post-anesthesia recovery settings. Lack of theoretical foundation is another major weakness. Empirical application of this measure in the interventions should be further explored.

Overall Evaluation of the Coding Systems

Table 2.7 presents the results of overall evaluation of the coding systems based on the SPP-ATF criteria. Four coding systems were deemed well-established assessments (OSBD, DPIS, CAMPIS, and CAMPIS-R); seven coding systems were deemed approaching well-established assessments (BAADS, MAISD, CAMPIS-SF, P-CAMPIS, Modified-CAMPIS, PACBIS, and CBCS-P); and four coding systems were deemed promising assessments (Parent Communication Typology, Parent Distance and Touch, CAMPIS-IV, and GRIDS). Additional information for the evaluation process can be found in Appendix 2.

Table 2.7. Overall Evaluation of the Observational Coding Systems of Parent-Child Interactions

Category	Level	Definition	Coding Systems in the Category
Well-established assessment	I	Two peer-reviewed articles	OSBD DPIS CAMPIS CAMPIS-R
	II	Allow critical evaluation and replication	
	III	Good validity and reliability	
Approaching well-established assessment	I	Two peer-reviewed articles	BAADS MAISD CAMPIS-SF P-CAMPIS Modified CAMPIS PACBIS CBCS-P
	II	Allow critical evaluation and replication	
	III	Vague or moderate validity and reliability information	
Promising assessment	I	One peer-reviewed article	Parent Communication Typology Interpersonal Distance and Touch Coding System CAMPIS-IV GRIDS
	II	Vague or moderate validity and reliability information	
	III	Allow critical evaluation and replication	

Note: BAADS = Behavioral Approach-Avoidance and Distress Scale; CAMPIS = Child-Adult Medical Procedure Interaction Scale; CAMPIS-IV = CAMPIS-Infant version; CAMPIS-SF = CAMPIS-Short Form; CAMPIS-R = CAMPIS-Revised; CBCS-P = Child Behavior Coding System-Post Anesthesia Care Unit; DPIS = Dyadic Prestressor Interaction Scale; GRIDS = Generation R Infant Distress Scale; MAISD = Measure of Adult and Infant Soothing and Distress; OSBD = Observational Scale of Behavioral Distress; PACBIS = Perioperative Adult Child Behavioral Interaction Scale; P-CAMPIS = Perioperative Child-Adult Medical Procedure Interaction Scale

Discussion

This study reported the results of the systematic review and evaluation of extant observational coding systems of parent-child interactions during painful procedures. Fifteen coding systems (from 16 studies) were identified and then systematically reviewed and evaluated using the APP-ATF criteria. Six of these coding systems were adapted from the original CAMPIS (Blount et al., 1989, 1997). The findings showed that an array of observational coding systems of parent-child interaction has been developed and applied in children within a variety of age groups and pain contexts (e.g., acute surgical pain, immunization-related pain, cancer-related procedural pain, chronic abdominal pain). Several of these observational systems including the CAMPIS /CAMPIS-R (Blount et al., 1989, 1997) and the PACBIS (Sadhasivam et al., 2010) have been used to guide the development of interventions and examine changes in the outcome

variables. The major limitations of these systems are lack of theoretical bases and under-representation of parent nonverbal behaviors in the coding schema.

Findings of this review provide detailed information on choosing observational coding systems during painful procedures that best fit target population, pain context, and research purpose. For instance, three coding systems were developed for use in infants, including the MAISD (Cohen et al., 2005), CAMPIS–IV (Blount et al., 2008), and GRIDS (Wolff et al., 2009). Also, three observational coding systems were developed for assessing child behavioral indicators of distress and two measures for assessing parent communication behaviors; the other 10 measures can be used to code both child and parent behaviors. Ong and colleagues (1995) addressed the importance of other information regarding understanding observational measures of interactions, such as clinical relevance, observational strategies, reliability and validity, and channels of communicative behavior. In this study, we gathered similar information for the use of observational coding systems on parent-child interactions. Therefore, this study reviewed the strengths and limitations of these measures based on this information, all of which can help clinicians and researchers choose appropriate measures. Exactly when and how these coding systems might be used to evaluate the outcomes of interventions regarding parent-child interactions in fitting pediatric populations requires further examination.

Multiple observational measures have been developed to code parent-child interactions during painful procedures and these coding systems address a variety of age and specific context situations. We evaluated the strengths of each system based on the APP-APT criteria, informed by well-established standards for psychometric properties. First, the psychometric properties of these identified coding systems have been reported, including indices of reliability and validity. Inter- and intra-rater reliability estimated by Cohen's kappa coefficient or ICC are standard

indicators of the reliability of observational measures (Ostor & Hart, 2013). According to Fleiss (1981), every coding system included in this review was judged to have at least a minimally acceptable level of inter-rater reliability ($\kappa > 0.6$). Construct validity (convergent validity, divergent validity, and sensitivity to change over time) was judged as being well-established for the majority of the coding systems (e.g., BAADS, CAMPIS/CAMPIS-R, and CAMPIS-SF). Therefore, the extant coding systems were evaluated as having acceptable to excellent psychometric properties. Future research should further examine the external validity of the newer observational coding systems (e.g., GRIDS, MAISD, and Parent Communication Typology). For the most part, these coding systems have been used in research. The CAMPIS and its derivatives have been used in children during various medical procedure–related contexts such as BMAs or LPs (Blount et al., 1989), immunizations (Blount et al., 1997; Manimala, Blount, & Cohen, 2000), voiding cystourethogram (Zelikovsky, Rodrigue, Gidyzc, & Davis, 2000), and physical therapy (Miller, Johanna-Murphy, & Zhelezniak, 2001).

The primary limitation of coding systems included in the review is that they lack a theoretical basis. Theory can provide the foundation to describe, understand, and explain specific concepts that emerge from observations of parent-child interactions in practice or research. Coding systems with clear theoretical bases offer concrete structures and domains that can guide the design and implementation of interventions that aim to support parent-child interactions that benefit both the child and the parent. Other limitations of these coding systems include that nonverbal behaviors (e.g., touch, proximity, and eye contact) are under-represented and that these systems are specific to an age group or clinical situation and were developed mainly in Western countries, thus limiting their use in other age, procedural, and cultural contexts.

We selected the SPP-ATF criteria to evaluate the eligible coding systems and only a small percentage of them (4/15; 26.7%) were deemed to be in the well-established assessment category. Among the coding systems in this category, the CAMPIS and CAMPIS-R met the criteria due to their use by a variety of researchers and their psychometric properties, and this finding is consistent with Blount and colleagues' (2008) work. Additionally, we judged the BAADS and CAMPIS-SF to be in the approaching well-established category. However, Blount et al. (2008) considered the BAADs and CAMPIS-SF to be in the promising assessment category. This difference in category is likely due to the ongoing use of these measures and accumulating evidence to support their psychometric robustness. Thus we recommend that observational coding systems should be reevaluated regularly.

To advance the use of observational coding systems for parent-child interaction in clinical practice and research, we have several recommendations. First, observational coding systems play critical roles in facilitating the design and evaluation of interventions. Blount and colleagues (2008) suggested further discovering the relationships between well-developed coding systems and interventions and thereafter designing target interventions based on the results of analyzed observations using these systems. According to this review, we found that the CAMPIS, CAMPIS-R, and PACBIS have been used to develop interventions that aimed to improve parent-child interactions and thus alleviate child distress. Future research should explore how the well-developed coding systems could be used to tailor and evaluate interventions. Second, theory-based measures are lacking. Measures that are developed based on theories could provide us an effective and operational way to design clinical interventions regarding parent-child interactions. Thus, the development of observational coding systems that are based on theory is a promising direction.

Third, coding systems that include codes for nonverbal behaviors are few in number (Peterson et al., 2007). Atkinson and colleagues (in press) found that parents with higher emotional availability showed more physical comforting and rocking behaviors, and they reported lower pain scores for their infants during immunizations. Given the influence of these parent nonverbal behaviors on treatment responses by infants or younger children (Atkinson et al., in press), further research is needed to develop observational systems that also include codes relevant to nonverbal behaviors and then use them to examine the influence of nonverbal parent behaviors on treatment responses to pain procedures in older children. Finally, multidimensional coding systems that more fully describe the complexity of parent-child interactions should be developed (Blount et al., 2008). Previous coding systems have included different interactive behaviors such as verbal and nonverbal behaviors. In this study, we have evaluated the use of verbal, nonverbal, or the combination of both types of behaviors for each observational coding system of parent-child interactions. We believe that observational coding systems of parent-child interactions should include not only verbal and nonverbal behaviors but also emotional behaviors because parental emotions and psychosocial factors can influence child behavioral responses during painful procedures.

Several limitations of this systematic review have to be addressed. Kazak and colleagues (1996) indicated that self-report and observational measures could be used together to fully understand parent-child interactions during painful procedures. The current systematic review did not include self-report measures, thus future systematic reviews might consider the use of mixed methods to study parent-child interactions during painful procedures and their outcomes. In addition, no standard criteria exist for the evaluation of observational coding systems. Although we chose the SPP-ATF criteria, they did not include standards regarding theoretical

basis, sample size, use in other cultural contexts, and so forth. These evaluation criteria should be expanded for use in future systematic reviews and other types of inquiry. Moreover, we only included studies that reported on the development and psychometric evaluation or use of a specific type of coding systems. Further evaluation of how these systems are used and performed in intervention research would provide further evidence to support their validity.

Conclusion

This is the first study to systematically review and evaluate extant observational coding systems of parent-child interactions during painful procedures. Information of 15 coding systems was extracted from these 16 studies included in the review and then evaluated using the SPP-ATF criteria and informed by psychometric standards. These observational coding systems were developed as means to assess parent-child interactions across different age groups and procedural contexts that typically involve pain. Among these 15 measures, three target child behaviors, two target parent behaviors, and 10 assess both parent and child behaviors. All of these coding systems had at least an acceptable reliability and some evidence for validity. Also, several coding systems have been used to inform the development of interventions to help children cope with painful procedures. However, only two coding systems had clear theoretical bases; furthermore, nonverbal behaviors were under-represented, especially in coding systems applicable to older children (ages 3–18 years) who are able to express themselves verbally. A small portion of the extant coding systems was deemed well-established based on the SPP-ATF criteria. Future research should include the development of a coding system based on theory and considers nonverbal interaction behaviors between children of all ages and their parents.

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CHAPTER 3. PARENT CARING RESPONSE SCORING SYSTEM (P-CaReSS) FOR CHILDREN DURING CANCER TREATMENT−RELATED PORT STARTS: ITS DEVELOPMENT AND PRELIMINARY PSYCHOMETRIC EVALUATION

Introduction

Reliable and valid interaction analysis systems (IASs) can capture parent interactions with their child during distressing and painful procedures that a child regularly endures as part of cancer therapy and outcome monitoring. Multiple IASs such as the Child-Adult Medical Procedure Interaction Scale-Revised (CAMPIS-R) (Blount et al., 1997) and CAMPIS-Short Form (CAMPIS-SF) (Blount, Bunke, Cohen, & Forbes, 2001) are available for assessing parent−child interactions during these procedures. The IASs can guide the design of interventions to improve parent−child interactions and thus decrease child's pain and distress, increase child treatment cooperation, and broaden our understanding of parent−child interactions in painful contexts (Blount et al., 2008). The majority of extant IASs have been shown to have good reliability and validity, and significant clinical relevance and utility (Blount et al., 2008). However, these systems have weaknesses, including lack of a theoretical basis (Blount et al., 1997, 2001), underrepresentation of parent nonverbal behaviors (Peterson et al., 2007), and being too lengthy for use in clinical practice (Blount et al., 1989, 2008). Using explicit theoretical basis to build an observational tool can guide the development of codes, their operational definitions, and the selection of theoretically-related variables.

Recently, parent nonverbal behaviors have been added to parent-child IASs. However, these systems are only restricted for use in children in particular age groups or in specific clinical conditions. For instance, the CAMPIS-Infant Version (CAMPIS-IV) consists of adult motoric

behaviors and verbal behaviors with infants during immunizations (Blount, Devine, Cheng, Simons, & Hayutin, 2008). Similarly, the perioperative CAMPIS (P-CAMPIS) includes 40 codes grouped into verbal and nonverbal interactions between children, parents, and medical staff in perioperative settings (Caldwell-Andrews et al., 2005).

Additionally, findings of studies regarding parent−child interactions are inconsistent, especially regarding the influence of parent verbal assurance and expressions of empathy on child treatment-related responses (Blount et al., 1989; Cline et al., 2006; McMurtry, McGrath, Asp, & Chambers, 2007). Possible explanations for these inconsistencies are: 1) use of different IASs that have similar codes with varying operational definitions and 2) these widely used codes might include subdomains that could affect the child in different ways (e.g., empathy includes both empathy concern and empathy distress [McMurtry et al., 2007; Penner et al., 2008]). With the increasing need for theory-based behavioral interventions to improve child quality of life including during cancer treatment−related procedures, developing an IAS that has a theoretical basis, consistent operational definitions, and ample representation of nonverbal parent behaviors is imperative. Appropriate theoretical basis could connect new knowledge to the vast body of relevant knowledge based on clear conceptual direction (DePoy & Gitlin, 1998). Theory will provide a lens to view what may be disconnected between individual interactions so that a more coherent view of how a parent interacts with the child is gained during painful procedures.

Theoretical Framework

Swanson's Theory of Caring provides a suitable basis for the development of observational coding systems. This middle-range theory has been used as a basis for research and clinical practice, and for instrument development (Andershed & Olsson, 2009; Swanson, 1999). This theory comprises five caring domains: Knowing (i.e., "Striving to understand an event as it

has meaning in the life of the other"), Being with (i.e., "Being emotionally present to the other"), Doing for (i.e., "Doing for the other as he/she would do for oneself"), Enabling (i.e., "Facilitating the other's passage through life transitions and unfamiliar events"), and Maintaining Belief (i.e., "Sustaining faith in the other's capacity to get through an event or transition and face a future with meaning") (Swanson,1991). According to the Theory of Caring, when caregivers (e.g., parents) take the time to know, be with, do for, enable, and maintain belief, the care recipients (e.g., children) will feel a sense of wholeness—that is, they feel understood, valued, safe and comforted, capable of coping with life changes and unfamiliar events, and hopeful for the future (Swanson, 2013). Caring can ultimately influence well-being of the both the caregiver and the care recipient (Swanson, 1999a, 1999b; Swanson, Chen, Graham, Wojnar, & Petras, 2009), reducing both parent distress and child distress.

Swanson's caring domains provide an appropriate theoretical foundation to capture caring parent interaction behaviors toward their child during cancer treatment−related procedures. Because parents are human, not all parenting behaviors during their child's painful procedures can be construed as caring directed toward the child. That is, some parent behaviors might be self-protective. Thus, we added a non-caring domain based on previous literature and existing measures. By adding a non-caring domain, we can account for parent behaviors that reflect their escalating distress and diminishing capacity to engage in pro-social behaviors to promote their child's well-being. The relationships between Swanson's theory and study variables in this study are shown in Figure 3.1.

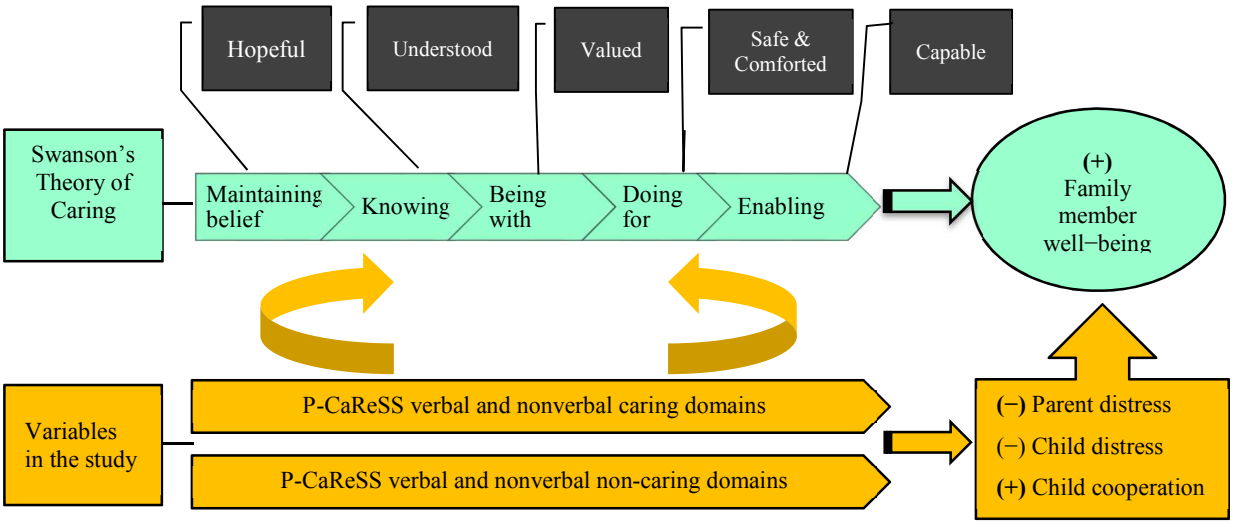

Figure 3.1. Swanson's Theory of Caring and relationships to study variables.

Developing a new IAS can facilitate further understanding of how parents interact with their child during painful procedures. A well-developed IAS can help researchers and clinicians assess parent interaction behaviors and design potential interventions during painful procedures (Blount et al., 1989, 1997; Sadhasivam et al., 2010). The purpose of this study was to describe the development, refinement, and preliminary psychometric evaluation of the IAS referred to as the Parent Caring Response Coding System (P-CaReSS). The P-CaReSS differs from existing observational IASs in that it captures parent verbal, nonverbal, and emotional indicators based on Swanson's Theory of Caring. Our specific study aims were to: 1) develop an observational parent interaction coding system (i.e., P-CaReSS) based on Swanson's Theory of Caring, 2) determine whether the operational definitions of P-CaReSS can be applied reliably to parent interaction with a child undergoing cancer treatment−related port starts, and 3) examine the relationships between the behavioral codes in the P-CaReSS and three theoretically-related

variables assessed by various raters: parent distress (rated by parent, medical staff, and trained observer), child distress (rated by parent, medical staff, trained observer, and child), and child cooperation (rated by parent, medical staff, and trained observer).

Methods

Design

The study used a prospective design with self-reported measures and repeated observational measures.

Sample

For the development (item generation) and preliminary testing (inter-rater reliability [IRR] and validity) of the P-CaReSS, we used two sources of data: a publicly available documentary film called "The Waiting Room" (Nicks, 2012) and two sub-samples from the primary study titled "Resources, Parent-Child Communication and Adjustment to Pediatric Cancer" (RO1CA138981; PI: L. Penner).

Data source 1. Six video clips were extracted from the previously mentioned documentary film. These clips showed a pair of parents interacting with their 9-year-old daughter as she underwent procedures (i.e., venipuncture and computerized tomography scan) during an Emergency Room visit. These video clips were used to generate preliminary behavioral codes for the P-CaReSS.

Data source 2. The primary study (RO1CA138981; PI: L. Penner) recruited 156 families with children recently diagnosed with cancer and includes two study phases. The aims of phase 1 were to: 1) examine the relationships between family resources (i.e., social, personal, and fiscal/material resources) and parent's and child's psychosocial well-being, 2) examine the relationships between family resources and parent-child communication during oncology clinic

visits, and 3) study the influence of parent-child communication on child and parent responses to procedures and subsequent psychosocial adjustment. The aim of phase 2 was to examine the relationships between these variables and parent's and child's responses to procedures. Eligibility criteria of participants in the study were: 1) child (ages 3−12 years) and adult primary caregivers (hereafter "parents"), 2) child received active cancer treatment, and 3) child had clinically indicated port starts, lumbar punctures (LPs), or bone marrow aspirations (BMAs).

In the current study, two sub-samples were chosen from Penner's study sample (N = 83). First, video-recording data provided by 29 parent-child dyads were chosen. Participants selected for this study had one video-recorded port start. These participants' port start videos were used to refine the P-CaReSS (13 videos), train data coders (5 videos), and test the IRR (11 videos). Second, 43 families with at least two video recordings of port start were chosen to test the relationships between the P-CaReSS and three person-reported measures: parent distress, child distress, and child cooperation.

P-CaReSS Developing and Testing Procedure

The P-CaReSS was developed and tested in accordance with procedures described by Sharpe and Koperwas (2003) and Chorney et al. (2015). The developing procedural steps include: a) defining the purposes, b) deciding the feature of behavioral codes, c) formulating a preliminary coding system, d) constructing the operational definitions, and e) refining the P-CaReSS. The testing procedural steps include: a) training coder, b) coding process, c) reliability analysis, and d) validity analysis (Table 3.1).

Table 3.1. Developing and Testing the P-CaReSS

Developing Process	
a. Defining the purposes	• Who will use the coding system? • What will be the general goals or purposes of the project?
b. Deciding the feature of behavioral codes	• Whether the codes are exclusive and inclusive from each other? • Whether the codes are physical-based or social-based? • What will be the size and complexity of the coding system?
c. Formulating a preliminary coding system	• What behavioral codes/labels will be used in the coding system? • What sources will be used to get these codes/labels?
d. Constructing the operational definitions	• How will these behavioral codes be defined based on their features? • Whether the definitions of these codes meet the criteria: objectivity, clarity, and complete? • What will be included in the coding manual?
e. Refining the coding system	• Whether the operational definitions will work in the target project? • What is still missing in the coding system?
Testing Process	
a. Training coder	• What are the required qualifications for coders to use the coding system? • What will be the "gold standard" to evaluate the coder as sufficiently trained?
b. Coding process	• Who will be the primary and secondary coders? • What will be the sample size? • How will the coding discrepancies between primary and secondary coders be solved?
c. Reliability analysis	• Which measure of agreement will be used? • What will be the criteria for the reliability indices?
d. Validity analysis	• What measure of validity will be used? • How the selected measure of validity will be analyzed? • What will be the criteria for the validity indices?

P-CaReSS developing process.

a) Defining the purposes. The purpose of developing the P-CaReSS was to capture parent interaction behaviors during distressing and painful procedures such as those regularly experienced by children with cancer.

b) Deciding the feature of the codes. Social-based codes were used in the P-CaReSS. Bakeman and Gottman (1997) established two types of observational codes: physical- and social-based codes. Physical-based codes apply to explicit physical actions such as the parent touching the child or the child crying; social-based codes apply to researcher perceptions of a social process. Painful procedures occur in a social context wherein children and parents engage in a

social process in which parent behaviors have meaning to their children. Therefore, social-based codes are suitable for studying parent interaction behaviors toward their child. Additionally, all the verbal, nonverbal, and emotional behaviors from the P-CaReSS were mutually exclusive (i.e., only one code can be given to a particular event) and exhaustive (i.e., there is some code for every event).

c) Formulating a preliminary coding system. A hybrid approach of inductive and deductive coding was used to formulate the preliminary observational codes for the P-CaReSS (Fereday & Muir-Cochrane, 2006). The observational codes were inductively generated from "The Waiting Room" (Nicks, 2012); meanwhile, the definitions and domains of Swanson's Theory of Caring and its applications were understood by reviewing previous studies guided by this theory and personal communication with the theorist (Dr. Kristen Swanson) (Figure 3.2 S_1). Then, the inductively derived behavioral codes were deductively assembled into domains informed by Swanson's Theory of Caring (Figure 3.2 S_2). The challenges of using this theory in the development of the behavioral codes were discussed with the theorist so that appropriate strategies were used to address them. For instance, both the category (e.g. "Doing for" or "Enabling") definitions and their intended outcomes (e.g., "safe and comforted" or "capable") are considered when it is hard to distinguish whether a specific behavioral code belongs to the "Doing for" or "Enabling" domains.

d) Constructing the operational definitions. Operational definitions were created for each domain (i.e., caring and non-caring) and observable codes based on Swanson's Theory of Caring, previous literature and measures. All the operational definitions had to meet the following criteria: objectivity, clarity, and completeness (Sharpe & Koperwas, 2003).

e) Refining the system. The behavioral codes and operational definitions were refined by applying them to code video-recordings of 13 children undergoing cancer treatment−related port starts. This sample of children was randomly selected from a sub-sample of children with one video-recorded port start. Based on this experience, all the behavioral codes were refined, and the P-CaReSS and its coding manual were prepared for further testing (Appendices 3.1 and 3.2).

P-CaReSS testing procedure.

a) Training coders. The first author and one PhD-prepared research assistant (RA) were trained by one research manager to code video data using the StudioCode© software (StudioCode Business Group, Australia). The StudioCode© software is a video analysis tool that can capture, categorize, analyze, and archive video data. The training protocol and coding manual are shown in Appendices 3.2 and 3.3. Five randomly selected videos were provided to train the coders and coding results were compared between both coders for each video. After the RA was trained to use the observational P-CaReSS by the first author (JB), both coders used the P-CaReSS to code each independent video. The coders met daily to resolve coding disagreements during the training period. The RA was considered sufficiently credentialed to conduct coding when she achieved 80% agreement with the first author's coding (Sharpe & Koperwas, 2003).

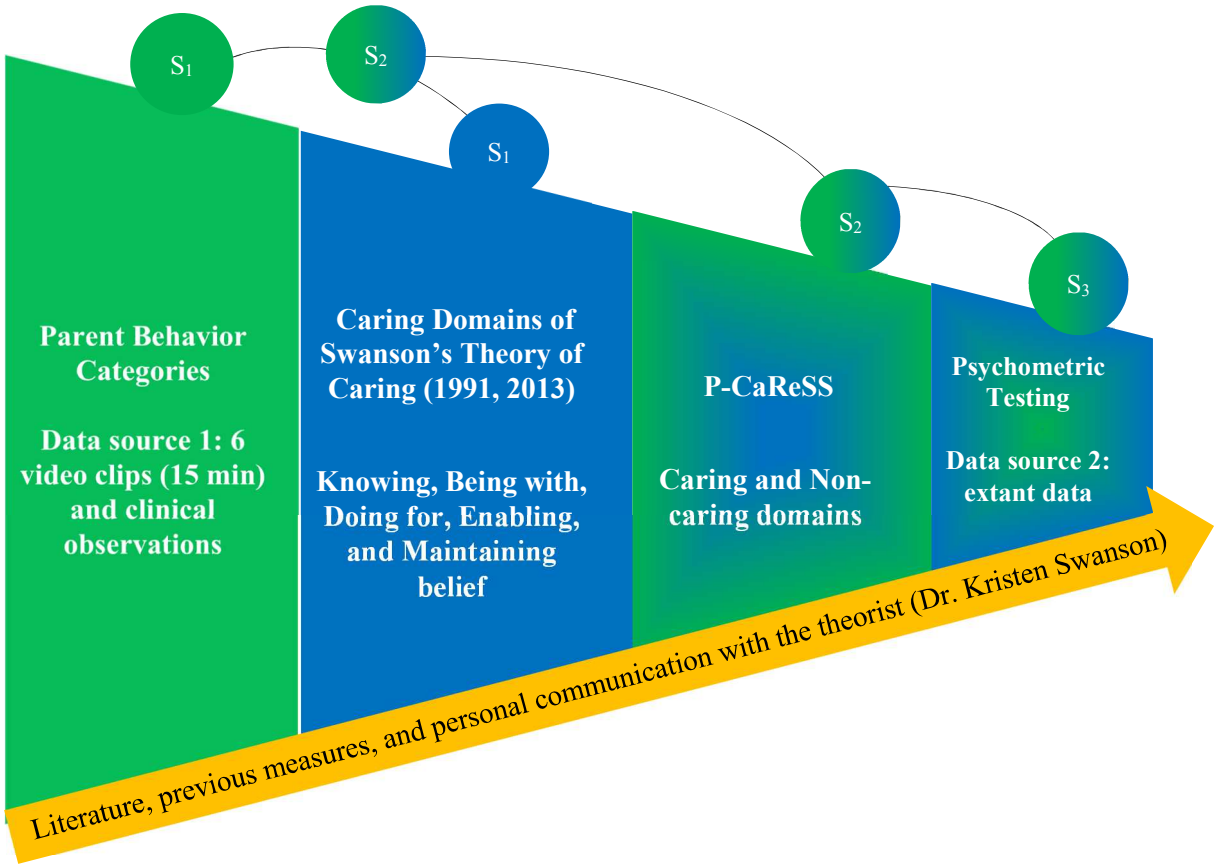

Figure 3.2. Formulating the P-CaReSS.

S_1: Parent behaviors were inductively identified from six video clips (GREEN); the caring domains of the Swanson's Theory of Caring were reflected (BLUE);
S_2: Parent behavioral codes identified in S_1 were deductively constructed based on Swanson's Theory of Caring, resulting in the caring and non-caring domains of the P-CaReSS;
S_3: Reliability and validity testing of the P-CaReSS by extant dataset. Through all the **S_1-S_3**, previous literature and measures, and personal communication with the theorist (Dr. Kristen Swanson) were continuously used to support the development of the P-CaReSS.
Note: P-CaReSS = Parent Caring Response Scoring System; S_1 = Step 1; S_2 = Step 2; S_3 = Step 3

b) Coding process. After training was successfully completed, both coders rated the video data using the StudioCode© software. The timed-event coding method was used to capture frequency, duration, and timing of behavioral codes (Bakeman & Gottman, 1997). For the verbal behaviors, onset times were recorded in the StudioCode© timeline, therefore providing frequency data for verbal "event" codes. Because nonverbal behaviors can co-occur along with verbal and emotional behaviors and be of substantial durations, onset and offset times for these behaviors were recorded as "state" codes, leading to frequency and duration of occurrence of these behaviors. The emotional behavior is a categorical variable with three levels (i.e., caring [positive emotions], neutral, and non-caring [negative emotions]). Each selected video period (e.g., during port start) was given a global level as one of three levels. The coders met weekly during the coding period to review coding and resolve disagreements through discussion and reviewing evidence from the videos.

c) Reliability analysis. To estimate the IRR, either the percent agreement or Cohen's kappa was calculated. One PhD-prepared data manager programed the IRR calculation syntaxes in the StudioCode©. Typically, a random sampling assigned to 10% − 30% of the video data is adequate to examine IRR when there is more than one rater/coder (Ostrov & Hart, 2013). In this study, the video data from 11 participants (13%) in Penner's primary study (N = 83) were used to calculate the IRR. Point-by-point percent agreement was computed to present the IRR for the verbal behavioral codes because these behaviors were regarded as frequency data (Formula a); percent agreement regarding duration was calculated as the measure of IRR for the codes that represented nonverbal behaviors because these behaviors were coded as duration data (Kaczorowski, 2015; Sharpe & Koperwas, 2003); and Cohen's kappa was estimated as the measure of IRR for the codes that represent behavioral expression of emotion because it is a

categorical variable (Formula b) (Bakeman & Gottman, 1997). The IRR is considered to be at an adequate level when the measure value is above 0.80 (Sharpe & Koperwas, 2003).

$$\frac{\text{Number of Agreements}}{\text{Number of Agreements + Number of Disagreements}} \times 100$$

$$= \text{Percent Agreement} \qquad \text{(Formula a)}$$

$$\frac{\text{P(Agreement)} - \text{P(Chance Agreement)}}{1 - \text{P(Chance Agreement)}}$$

$$= \text{Kappa value} \qquad \text{(Formula b)}$$

d) Validity analysis. Given non-normal distributions, Spearman rank-order correlations were used to examine the relationships between parent interaction behaviors in the P-CaReSS and parent distress, child distress, and child cooperation. The revised Wong-Baker Faces scale was used to assess parent distress and child distress. The rating anchors of these faces are from "no distress at all" (1) to "the worst distress" (6). Child cooperation was assessed by a global measure with anchors from "totally uncooperative" (1) to "totally cooperative" (7). Its total score ranges from 1 to 7. Both scales show good reliability in previous studies (Peterson et al., 2014).

Results

P-CaReSS

The P-CaReSS comprises 18 items that describe three types of parent interaction behaviors: verbal (11 items), nonverbal (6 items), and emotional indicators (1 item). Parent verbal and nonverbal behaviors are both grouped into five caring domains—knowing (1 item), being with (3 items), doing for (3 items), enabling (4 items), maintaining belief (2 items)—and one non-caring domain (4 items). Emotional indicator is designed to capture parent emotion status during cancer painful procedures. Parent emotional behavior is categorized into three levels (i.e., caring [positive], neutral, and non-caring [negative]). Detailed information regarding the P-CaReSS is presented in Table 3.2.

Table 3.2. The Parent Caring Response Scoring System (P-CaReSS)

Domain	Specific Item
Verbal (11 items)	
Knowing: Striving to understand an event as it has meaning in the life of the child	Avoiding assumptions/seeking cues (AA)
Being with: Being emotionally present to the child	Sharing feelings (SF)
Doing for: Doing for the child as he/she would do for oneself	Protecting (PR) Comforting (CO)
Enabling: Facilitating the child's passage through life transitions and unfamiliar events	Informing/explaining (IE) Validating (VA) Supporting/allowing (SA)
Maintaining belief: Sustaining faith in the child's capacity to get through an event or transition	Believing in/holding in esteem (BE)
Non-Caring: Showing less parental physical and emotional presence/engagement to the child; leading increasing burdens to the child	Burdening by emotions/intrusive questions (BI) Apologizing (AP) Criticizing (CR)
Other	Non-procedure related talk/questions
Nonverbal (6 items)	
Being with: Being emotionally present to the child	Eye contact (EC) Distance close enough to touch (DC)
Doing for: Doing for the child as he/she would do for oneself	Comforting (NCO)
Enabling: Facilitating the child's passage through life transitions and unfamiliar events	Supporting/allowing (NSA)
Maintaining belief: Sustaining faith in the child's capacity to get through an event or transition	Believing in/holding in esteem (NBE)
Non-Caring: Showing less parental physical and emotional presence/engagement to the child; leading increasing burdens to the child	Conveying less availability (LA)
Emotional (1 item)	
Caring: Positive emotions	Warm, friendly, loving, tender Happy, laughing, joking, joyful
Neutral	Matter of fact, neutral
Non-Caring: Negative emotions	Anxious, nervous, scared, fear Frustrated, depressed, exhausted, lost, sad Angry, hostile, annoyed, irritated

Support for Reliability

Participants. Eleven children with one video-recorded port start were selected from Penner's primary study (N = 83) to examine the IRR of P-CaReSS. These 11 children had a mean age of 6.1 years (SD = 2.7). Parents of these children had a mean age of 30.7 years (SD = 5.0). Table 3.3 describes the demographic and clinical data for these participants.

Table 3.3. Participants for the Inter-Rater Reliability Analysis

Variable	Mean (Standard Deviation)	Range
Child		
Child age, year	6.1 (2.7)	3−12
Child age at diagnosis, year	6.0 (2.9)	2−12
Number of port starts in past 2 months	18 (11)	1−30
Gender, n (%)		
Female	4 (36.4)	
Male	7 (63.6)	
Diagnosis of Acute Lymphocytic Leukemia, n (%)	11(100)	
Race, n (%)		
White	9 (81.8)	
Black or African American	2 (18.2)	
Parent		
Age, year	30.7 (5.0)	23−37
Gender, n (%)		
Female	10 (90.9)	
Male	1 (9.1)	
Race, n (%)		
While	8 (72.7)	
Black or African American	2 (18.2)	
American Indian/Alaska Native	1 (9.1)	
Marital status, n (%)		
Married	6 (54.5)	
Never married	1 (9.1)	
Separated	1 (9.1)	
Divorced	1 (9.1)	
Domestic partner	1 (9.1)	
Education status, n (%)		
Some high school	2 (18.2)	
Completed high school or GED	1 (9.1)	
One or two years of college (no degree)	3 (27.3)	
Completed Associate's degree or Trade School	2 (18.2)	
Completed Bachelor's degree	3 (27.3)	
Household annual income, n (%)		
Less than $10, 000	2 (18.2)	
$10, 000 ~ $39, 999	5 (45.5)	
$40, 000 ~ $ 59, 999	1 (9.1)	
$60, 000 ~ $100, 000	2 (18.2)	
Greater than $100, 000	1 (9.1)	

Note: GED = General Educational Development

Inter-rater reliability. On average, the point-by-point percent agreement was 0.83 for verbal behavioral codes (range 0.62 ~ 1.00); the average percent agreement was 0.80 for nonverbal behavioral codes (range 0.57 ~ 0.99); and the percent agreement was 0.91 with a kappa value of 0.81 for the emotional behavior. The average percent agreement was 0.82 for the

P-CaReSS overall, supporting its favorable IRR to assess parent interaction behaviors during port starts (Table 3.4). Detailed IRR information for each behavioral code is reported in Appendix 3.

Table 3.4. Inter-Rater Reliability of the P-CaReSS

Domain	Verbal *	Nonverbal **	Emotional
Point-by-point percent agreement	0.62−1.00	NA	NA
Duration percent agreement	NA	0.57−0.99	NA
Average for each domain	0.83	0.80	0.91
Kappa value	NA	NA	0.81
Average of the whole measure		0.82	

Note: NA = not applicable; P-CaReSS = Parent Caring Response Scoring System
***** 1 behavioral code with IRR < 0.7; ****** 2 behavioral codes with IRR < 0.7

Support for Validity

Participants. Forty-three families with at least one video-recorded port start were selected from Penner's primary study (N=83) to establish preliminary support for the validity of the P-CaReSS. These 43 children had a mean age of 6.4 years (SD = 3.0). Parents of these children had a mean age of 34.4 years (SD = 7.1). Table 3.5 describes the demographic and clinical data for these participants.

Validity. To support the validity of the P-CaReSS, our study hypotheses were: 1) parent caring behaviors will show positive correlations with parent distress and child distress but negative correlations with child cooperation and 2) parent non-caring behaviors will show positive correlations with parent distress, child distress, and negative correlation with child cooperation. Spearman's correlations between the behavioral codes in the P-CaReSS and measures of three theoretically relevant variables are displayed in Table 3.6.

Table 3.5. Participants for the Validity Analysis

Variable	Mean (Standard Deviation)	Range
Child		
Child age, year	6.4 (3.0)	3−12
Child age at diagnosis, year	6.1 (3.2)	2−12
Number of port starts in past 2 months	10 (8)	1−30
Gender, n (%)		
Female	17 (39.5)	
Male	26 (60.5)	
Diagnosis, n (%)		
Acute Lymphocytic Leukemia	28 (65.1)	
Wilms' Tumor	6 (14.0)	
Hodgkin's Lymphoma	1 (2.3)	
Non-Hodgkin's Lymphoma	2 (4.7)	
Sarcoma (unspecified)	2 (4.7)	
Other cancer	4 (9.2)	
Race, n (%)		
White	31 (72.1)	
Black or African American	8 (18.6)	
Other	4 (9.3)	
Parent		
Age, year	34.4 (7.1)	20−54
Gender, n (%)		
Female	34 (79.1)	
Male	9 (20.9)	
Race, n (%)		
While	32 (74.4)	
Black or African American	7 (16.3)	
American Indian/Alaska Native	4 (9.3)	
Marital status, n (%)		
Married	27 (62.8)	
Never married	5 (11.6)	
Separated	1 (2.3)	
Divorced	8 (18.6)	
Domestic partner	1 (2.3)	
Widowed	1 (2.3)	
Education status, n (%)		
Middle school	2 (4.7)	
Some high school	3 (7.0)	
Completed high school or GED	7 (16.3)	
One or two years of college (no degree)	9 (20.9)	
Completed Associate's degree or Trade School	8 (18.6)	
Three or four years of college or less	3 (7.0)	
Completed Bachelor's degree	4 (9.3)	
Completed Master's degree or above	7 (16.3)	
Household annual income, n (%)		
Less than $10, 000	8 (18.6)	
$10, 000 ~ $39, 999	13 (30.3)	
$40, 000 ~ $ 59, 999	3 (7.0)	
$60, 000 ~ $100, 000	10 (23.3)	
Greater than $100, 000	6 (14.0)	

Twelve behavioral codes of the P-CaReSS were positively and significantly correlated with child distress as rated by at least one type of rater (parent, medical staff, observer or child) (r_s = 0.34 – 0.74) and less availability was negatively and significantly correlated with child distress as rated by at least one type of rater (r_s = -0.34 – -0.58). Three caring behavioral codes (i.e., sharing feelings, comforting, nonverbal believing in/holding in esteem) and one non-caring behavioral codes of the P-CaReSS (i.e., apologizing) were not significantly correlated with any rating of child distress.

In addition, nine behavioral codes of the P-CaReSS were positively and significantly correlated with parent distress as rated by at least one type of rater (r_s = 0.34 – 0.63) and less availability was negatively and significantly correlated with parent distress as rated by at least one type of rater (r_s = -0.52 – -0.58).

Moreover, ten behavioral codes of the P-CaReSS were negatively and significantly correlated with child cooperation as rated by at least one type of rater (parent, medical staff or observer) (r_s = -0.34 – -0.78) and parent less availability was positively and significantly correlated with child cooperation as rated by at least one type of rater (r_s = 0.34 – 0.43).

Table 3.6. Spearman Correlations between the P-CaReSS Behavioral Codes and Parent Distress, Child Distress and Child Cooperation

		Verbal Behaviors												Nonverbal Behaviors				
		Knowing	Being With	Doing For		Enabling			Maintaining Belief		Non-Caring			Being With	Doing For	Enabling	Maintaining Belief	Non-Caring
Variable	**T**	**AA**	**SF**	**PR**	**CO**	**IE**	**VA**	**SA**	**BE**	**BI**	**AP**	**CR**	**EC**	**DC**	**NCO**	**NSA**	**NBE**	**LA**
Parent-report child distress	1	0.25	-0.13	0.04	0.25	0.21	0.30	**0.58****	0.16	**0.40***	0.18	0.10	0.21	**0.37***	0.23	**0.51****	NA	-0.25
	2	0.07	0.07	**0.43****	0.06	**0.35***	**0.35***	**0.66****	**0.34***	0.19	-0.07	0.10	0.26	0.27	0.18	**0.44****	0.23	**-0.43****
	3	0.22	0.13	**0.42***	0.00	0.26	**0.45***	**0.63****	**0.43***	0.15	-0.07	**0.43***	0.20	**0.49****	0.14	**0.58****	0.08	**-0.48****
Medical staff-report child distress	1	0.13	-0.14	-0.16	0.16	0.20	**0.41***	**0.44****	0.27	0.31	0.12	-0.02	0.00	0.27	0.03	**0.48****	NA	-0.23
	2	0.27	0.17	**0.49****	0.16	**0.45****	**0.42***	**0.73****	**0.34***	0.21	0.04	0.15	0.21	**0.38***	0.15	**0.68****	0.13	**-0.51****
	3	0.19	-0.01	0.27	0.01	0.21	0.23	**0.49****	0.31	0.09	0.28	**0.38***	0.14	0.28	0.11	**0.38***	-0.01	**-0.37***
Observer-report child distress	1	0.16	-0.06	0.04	0.05	0.14	0.21	**0.56****	0.32	0.19	-0.20	0.20	0.22	0.16	0.17	0.25	NA	-0.15
	2	0.14	0.16	**0.47****	0.08	**0.43****	**0.41***	**0.69****	0.28	0.27	0.02	0.05	0.20	0.22	0.16	**0.58****	0.21	**-0.34***
	3	**0.36***	0.08	**0.39***	0.28	0.24	**0.56****	**0.74****	0.28	0.17	0.27	0.33	0.22	**0.63****	**0.38***	**0.64****	-0.11	**-0.52****
Child-report child distress	1	0.17	-0.23	0.02	0.16	0.17	0.35	**0.61****	0.06	**0.48****	0.25	-0.05	0.08	**0.44***	0.20	**0.52****	NA	-0.31
	2	0.12	0.29	**0.50****	0.14	**0.44***	**0.40***	**0.70****	**0.36***	0.28	0.11	0.11	**0.39***	**0.46****	0.12	**0.58****	0.20	**-0.58****
	3	0.12	0.11	0.28	-0.11	0.10	0.27	**0.62****	**0.52****	0.08	0.08	**0.44***	0.16	0.36	0.10	**0.47***	0.09	**-0.41***
Parent-report parent distress	1	0.09	0.17	0.03	0.18	0.22	0.17	**0.49****	0.17	0.14	-0.02	0.14	0.02	0.16	0.18	**0.46****	NA	-0.22
	2	0.15	0.14	0.13	0.03	0.27	**0.39***	**0.42***	0.24	0.25	-0.08	0.23	0.16	0.14	0.14	**0.41***	0.30	-0.24
	3	0.23	0.20	0.33	0.18	0.28	**0.41***	**0.60****	**0.54****	0.22	-0.20	0.24	0.18	**0.47****	0.10	**0.63****	0.32	**-0.58****
Medical staff-report parent distress	1	0.32	-0.18	-0.26	0.09	0.20	**0.36***	**0.43***	**0.40***	0.20	0.14	0.02	0.03	0.25	0.08	**0.43***	NA	-0.31
	2	0.11	0.14	**0.36***	0.08	0.20	0.31	**0.47****	0.21	0.27	-0.12	-0.03	0.08	**0.36***	0.15	**0.50****	0.27	**-0.52****
	3	-0.07	0.26	0.04	0.23	**0.52****	0.35	0.29	**0.40***	0.08	-0.15	0.35	0.08	0.11	0.19	0.26	0.14	-0.20
Observer-report parent distress	1	-0.04	0.29	0.06	-0.13	-0.12	0.08	0.26	0.18	0.06	-0.07	0.30	0.10	-0.18	0.15	-0.26	NA	0.23
	2	0.17	0.23	**0.39***	0.09	0.18	0.07	**0.39***	**0.34***	**0.38***	-0.06	0.03	**0.44****	-0.03	-0.07	0.15	0.30	-0.15
	3	0.35	-0.06	**0.44***	0.02	-0.07	0.23	0.32	-0.09	-0.04	0.13	0.13	0.04	0.16	0.14	0.29	-0.22	-0.12
Parent-report child cooperation	1	-0.21	0.20	0.16	-0.32	-0.20	-0.33	**-0.55****	**-0.42***	-0.29	-0.01	-0.14	-0.13	-0.30	-0.20	-0.32	NA	0.27
	2	-0.24	-0.15	**-0.37***	-0.09	**-0.39***	**-0.37***	**-0.69****	-0.24	-0.25	-0.15	-0.13	-0.15	-0.18	-0.03	**-0.42***	-0.16	0.28
	3	**-0.51****	0.11	-0.23	-0.01	0.09	**-0.44***	**-0.49****	-0.29	-0.06	-0.02	0.06	-0.25	**-0.55****	-0.27	**-0.47****	0.20	0.36
Medical staff-report child cooperation	1	-0.32	0.24	0.00	-0.30	-0.23	**-0.49****	**-0.54****	-0.21	**-0.39***	-0.13	-0.20	-0.17	**-0.48****	-0.20	**-0.49****	NA	**0.37***
	2	-0.13	-0.20	**-0.43****	-0.15	**-0.40***	**-0.34***	**-0.78****	-0.29	-0.26	-0.21	-0.18	-0.19	-0.32	-0.23	**-0.60****	-0.26	**0.43****
	3	-0.04	-0.21	**-0.38***	0.05	-0.12	-0.21	**-0.57****	**-0.37***	-0.16	-0.20	**-0.48****	-0.19	-0.19	-0.26	-0.28	-0.07	0.19
Observer-report Child Cooperation	1	-0.20	0.11	-0.11	-0.29	-0.30	-0.32	**-0.67****	**-0.34***	**-0.35***	0.01	-0.19	-0.16	**-0.38***	-0.24	**-0.44****	NA	**0.36***
	2	-0.15	-0.15	**-0.46****	-0.18	**-0.43****	**-0.46****	**-0.74****	**-0.37***	**-0.36***	0.08	-0.13	-0.27	-0.19	-0.16	**-0.48****	-0.15	0.30
	3	-0.16	-0.26	**-0.46***	-0.34	-0.28	**-0.62****	**-0.48****	0.03	-0.29	-0.12	**-0.38***	-0.27	**-0.48****	-0.27	**-0.38***	-0.06	0.32

Note: AA = Avoiding assumptions/seeking cues; AP = Apologizing; BE = Believing in/holding in esteem; BI = Burdening by emotions/intrusive questions; CO = Comforting; CR = Criticizing; DC = Distance close to touch; EC = Eye contact; IE = Informing/explaining; LA = Conveying less availability; NBE = Believing in/holding in esteem; NCO = Comforting; NSA = Supporting/allowing; P-CaReSS = Parent Caring Response Scoring System; PR = Protecting; SA = Supporting/Allowing; SF = Sharing feelings; T = time-point; VA = Validating

Discussion

The purpose of this study was to develop and test an observational coding system (i.e., P-CaReSS) that captures parent interaction behaviors toward their child during cancer treatment−related port starts. The new P-CaReSS was developed based on Swanson's Theory of Caring and can categorize parent behaviors during child's port starts into caring and non-caring domains. In addition, this observational tool captured not only parent verbalizations but also parent nonverbal and emotional behaviors, both of which have been rarely included in previous parent interaction tools such as the CAMPIS-R and CAMPIS-SF (Blount et al., 1997, 2008). The P-CaReSS is a novel tool that is developed with clear theoretical basis, which can provide the potential to guide interventions to help children cope with painful procedures from a caring perspective.

As a complex phenomenon, parent interaction with their child during painful procedures can be determined by many factors. A recent systematic review reported that more than 30 factors can influence child distress level during painful procedures (Racine et al., 2015). Parent-related factors are significant predictors of this distress. Being informed by Swanson's theory, this new coding system (i.e., P-CaReSS) can provide a structural approach to describing parent behaviors during their child's painful procedures, and also a potential guide of theory-based assessments and tailored interventions to enhance parent interaction behaviors and, thereafter improve their child's experience such as lower levels of child pain and distress but higher level of child cooperation during painful medical procedures.

It is feasible to develop an observational coding system based on a middle-range theory. The P-CaReSS was developed using both inductive and deductive coding strategies. Inductively, the behavioral codes in the P-CaReSS were formulated based on general extractions from extant

video clips, previous literature, and extensive clinical observations; these resources enrich the pool of parent behavioral codes and increased our view of parent interaction behaviors with their child. Deductively, the generated observational codes in the P-CaReSS were structured in accordance with the domains of Swanson's Theory of Caring. This theory also informs the development of operational definitions for behavioral codes in each domain. Moreover, the development of the P-CaReSS followed the practical guidelines of developing and modifying observational measures for use in children (Bakeman & Gottman, 1997; Chorney et al., 2015). Consequently, this study provides an exact exemplar for the development of an observational coding system based on a middle-range theory and current instrument development guidelines.

The P-CaReSS shows acceptable to excellent reliability for use by two raters. The average percent agreements were above 80% for verbal, nonverbal, and emotional domains, as well as for the total P-CaReSS. The emotional behavior showed excellent kappa value in this study ($\kappa = 0.81$). All of these values supported that the P-CaReSS is a reliable measure that can be used to capture parent interaction behaviors during cancer treatment–related port starts from a caring perspective.

Three verbal behaviors (i.e., sharing feelings, protecting, and apologizing) and one nonverbal behavior (i.e., maintaining belief/holding in esteem) did not occur during the IRR testing period. These findings are different from previous studies, which reported that apology is an interaction behavior that is frequently used by parents and healthcare providers during painful procedures (Blount et al., 1997; Cline et al., 2006). In this study, rare occurrences of these verbal and nonverbal behaviors can be explained as follows: 1) a 5-minute slice during port starts was selected from each video for the IRR testing, thus the slices might have under-represented the presence of these behaviors across the entire video; 2) the P-CaReSS is only adopted to assess

parent interaction behaviors, however other measures such as the CAMPIS-R and CAMPIS-SF were developed to assess adult (parents and healthcare staff)-child interactions. Chorney et al. (2013) found that parents used less apologizing behaviors than nurses, resulting in rare apologizing behaviors in this study. Although these four parent behaviors never occurred for IRR testing, we still suggest keeping and testing these behaviors in a large sample because these behaviors were built on theoretical basis and previous literature.

Significant correlations between the behavioral codes in the P-CaReSS and self-reported measures provide preliminary support for the construct validity of the P-CaReSS. As we expected, the behavioral codes in the P-CaReSS showed positive correlations with parent distress and child distress and negative correlations with child cooperation. These findings seem to be opposite to previous studies (Blount et al., 2001; Spagrud et al., 2008), which found that more parent coping-promoting behaviors can lead to lower levels of child pain and distress but more parental distress-promoting behaviors can lead to higher levels of child pain and distress. These differences can be explained as levels of parent distress and child distress possibly cue parents to use more interaction behaviors and level of child cooperation would cue less parent interaction behaviors during port starts. Noddings (1984) indicated caring occurring as a consequence of distress experienced by the caregiver, in which the caregiver acts to "discharge" their own distress and discomfort. Therefore, the P-CaReSS shows adequate preliminary reliability and validity and can be used in future research about cancer treatment–related port starts.

This study has theoretical and methodological strengths. The P-CaReSS is an observational tool that was developed based on Swanson's Theory of Caring. This theory provides a means to build new knowledge based on current knowledge of parent-child interactions during painful procedures with coherent and theoretical directions. The tool can be

used to capture parent verbal, nonverbal, and emotional behaviors when parent interacts with their child during port starts. In addition, this tool is developed to describe parent behaviors using the timed-event coding method, which is more valid than other coding methods (e.g., interval and event coding) and provides unique opportunities for the analysis of sequential relationships between variables (Bakeman & Quera, 2011; Chorney, Garcia, Berlin, Bakeman, & Kain, 2010).

Several limitations have to be addressed in this study. First, the P-CaReSS was preliminarily examined in a small sample of homogenous children receiving cancer treatment–related port starts. The generalizability of this coding system should be cautious if used beyond children receiving port starts. Moreover, a thin-slice approach (i.e., 5 minutes) was applied in this study. Although this approach has been validated for use in the interaction and communication studies (Chorney et al., 2013; Henry & Eggly, 2013), there is no current empirical or theoretical guideline regarding how to choose the slices on parental behavior during painful medical procedures. It is possible that we will have different results if we select thin-slices from pre-procedure, procedure, and post-procedure rather than only from the procedure. Last, the validity of the P-CaReSS was examined in terms of its correlations with parent distress, child distress, and child cooperation. Future studies should examine concurrent and predictive validity with respect to other observational measures such as the CAMPIS-R (Blount et al., 1997) and Parent Communication Typology (Cline et al., 2006). The content validity of the P-CaReSS can be further tested from parent's and child's perspectives.

Identifying parent interaction behaviors and exploring their effects on child's treatment responses is an important step to develop evidence-based assessments and interventions to help children cope with distressing and painful medical procedures. Until now, multiple measures have been developed to assess parent interaction behaviors during these procedures. However,

the newly developed P-CaReSS contributes to parent-child interaction studies by adding new codes regarding parent nonverbal and emotional behaviors during the procedures. For example, the P-CaReSS lists some parent behaviors that are rarely described in previous studies such as personal distance and eye contact and confirms the value of these nonverbal behaviors in relieving child's levels of pain and distress during painful procedures. Building this new coding system opens an opportunity to examine the influence of parent interaction behaviors on child's treatment-related responses and develop theory-based intervention programs.

Conclusion

This study described the development of the observational P-CaReSS using the hybrid approach of inductive and deductive coding and testing its preliminary reliability (i.e., IRR) and validity. The new tool captures not only parent verbal behaviors but also nonverbal and emotional behaviors. A subgroup of children undergoing cancer treatment–related port starts was selected to test its psychometric properties. Its IRR was measured by the percent agreement and Cohen's kappa value and its validity was examined by the correlational analysis. It is feasible to develop an observational tool based on a middle-range theory−Swanson's Theory of Caring. The P-CaReSS is a reliable and valid tool that can be used to assess parent interaction behaviors during cancer treatment−related procedures. The psychometric properties of the P-CaReSS should be further tested in a larger sample of children with other cancer treatment−related painful procedures such as LPs and BMAs.

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CHAPTER 4. PARENT DISTRESS, CHILD DISTRESS, AND CHILD COOPERATION DURING CANCER TREATMENT−RELATED PORT STARTS: DOES PARENT INTERACTION BEHAVIOR MATTER?

Introduction

Approximately 12, 400 children and adolescents are diagnosed with cancer in the United States each year (Ward, DeSantis, Robbins, Kohler, & Jemal, 2014). These children have to endure continuous cancer treatment−related procedures such as port starts, lumbar punctures (LPs), and bone marrow aspirations (BMAs) for regular monitoring of disease extension or recurrence, treatment effectiveness, and treatment toxicities or side effects (Blount, Piira, Cohen, & Cheng, 2006; Pizzo & Poplack, 2010, p. 1263). Children reported more pain and distress from the painful procedures than cancer itself (Hedstrom, Haglund, Skolin, & von Essen, 2003). In long-term survivorship, prior traumatic experiences with distressing procedures can lead to the individual's avoidance of regular primary health care and essential monitoring for adverse effects of their cancer therapies (Pate, Blount, Cohen, & Smith, 1996). Parent negative experiences of their child's treatment-related painful procedures are associated with their development of anxiety and post-traumatic stress symptoms (PTSS) (Harper et al., 2014). Supportive care strategies that include pharmacological and non-pharmacological approaches and various combinations of both approaches have been developed to help children manage their responses to potentially painful medical procedures (Hockenberry et al., 2011; Uman et al., 2013).

Among these supportive care strategies, parent behavioral interactions during painful procedures have been widely studied. Previous research has shown that parent interaction behaviors during painful medical procedures can affect children's levels of pain and distress

(Blount et al., 1989; Cline et al., 2006). In particular, parent coping-promoting behaviors such as humor ("You are a little silly duck!") and commands of using coping strategies ("Use deep breathing now!" "Imagine you are superman with power!") can reduce children's levels of pain and distress (Blount et al., 1989; Blount, Bunke, Cohen, & Forbes, 2001). Conversely, parent distress-promoting behaviors such as empathy ("I know this is hard."), apologies ("I am sorry we did this for you!"), and reassurance ("You will be OK.") can exacerbate children's levels of pain and distress during painful procedures (Blount et al., 1989, 1990, 2001; Spagrud et al., 2008).

Although research has provided explicit evidence regarding how parent interaction behaviors can affect children's levels of pain and distress during painful medical procedures, the findings have been inconsistent, especially regarding the distress-promoting behaviors (e.g., empathy and reassurance). For instance, more recent studies than Blount's (1989, 1990) have showed that parent empathy and reassurance behaviors help children cope with cancer treatment−related procedures with lower levels of pain and distress as compared to child levels of pain and distress in the contexts of parent distancing and invalidating behaviors (Cline et al., 2006). Moreover, McMurtry and colleagues (2007) suggested that reassurance might consist of sub-concepts that could cause mixed outcomes for children during painful medical procedures. Penner et al. (2008) also investigated two subdomains of parent empathy (empathy concern and empathy distress) and found that parent empathy concern (e.g., "softhearted and warm") was negatively correlated with children's pain and distress and parent empathy distress (e.g., "upset and worried") was positively correlated with children's pain and distress during painful procedures. Further explorations of the mixed findings regarding these verbal behaviors are needed during painful medical procedures.

Moreover, parent nonverbal behaviors are rarely studied during cancer treatment−related procedures. In one of the few available studies, Peterson and colleagues (2007) found that parent supportive touch could significantly reduce children's pain and distress during cancer procedures, suggesting that parent nonverbal behaviors can help shape the child's experience. To our knowledge, parent nonverbal behaviors are not well represented in extant parent-child interaction coding systems, which might contribute to the seldom investigation of parent nonverbal interaction behaviors during these procedures.

Port starts are regularly recurring element of the treatment experience for children with cancer and are normally carried out by professional nurses with the parent present. Children can experience distress and, despite the parent or nurse's timely application of topical anesthetics to the skin over the child's port, even pain during port starts. They can see the needle advancing toward their chest and then feel pressure and sometimes pain as the needle is inserted. The painful and distressing nature of port starts can affect children's cooperation level. Although previous studies have provided evidence regarding the importance of caring parent-child interactions during painful medical procedures such as port starts (Blount et al., 1989; Cline et al., 2006), the majority of the studies described parent-child interaction behaviors in a cross-sectional (e.g., only one port start for each child) rather than a longitudinal way (e.g., repeated port starts over the cancer treatment trajectory for each child). These studies relied on correlational analyses but not on newer methods such as the time-window sequential analysis (Chorney, Tan, & Kain, 2013). Longitudinal study of parent-child interactions and the impact of parent interaction behaviors on child's distress and cooperation during port starts can fill the gap regarding how parent interaction behaviors evolve as the port starts are repeated over the course of the child's therapy and affect child responses in both the short and longer term. Understanding

parent-child interactions during port starts can provide evidence for health care providers to help parents cope effectively during port starts and reduce the adverse effects of the medical procedures on the parent's and child's well-being.

The purpose of this study was to examine parent-child interaction behaviors during repeated port starts by the time-window sequential analysis method. Our specific aims are to:

1. Examine changes in parent interaction behaviors over three-repeated port starts procedures.

H1: Parents caring interaction behaviors will increase over the repeated port starts.

2. Investigate relationships between parent interaction behaviors and parent distress, child distress, and child cooperation over three repeated port starts procedures.

H2: Parents will exhibit more caring interaction behaviors when parent has a higher level of distress, or when the child has a higher level of distress or a lower level of cooperation.

3. Examine temporal relations between parent interaction behaviors and child distress over the repeated port starts procedures.

H3: Children will express fewer distress behaviors within 5s of parent caring interaction behaviors than at any other time observed.

Methods

Overview

This study used a longitudinal observational design to conduct secondary analysis of an extant data set. The sample for the secondary analysis was selected from the primary study titled "Resources, Parent-Child Communication and Adjustment to Pediatric Cancer" (R01CA138981; PI: L. Penner). Participants in the primary study were children who had been diagnosed with cancer and their parents. These participants were recruited from pediatric oncology programs at

two major children's hospital in the United States. Study assessments including person-reported outcome measures and video-recordings of parent-child interactions. Data were collected at entry to the study (T_1), immediately before and after up to 3 treatment-related procedures (T_2–T_4), and at two follow-up assessments (i.e., 3 and 9 months after the last video-recorded treatment-related procedure) (T_5 and T_6). Treatment-related procedures at T_2, T_3, and T_4 were separated by at least 2 weeks but no more than 3 months. This secondary analysis of the data from the primary study employed data from T_1 to T_4. The study was reviewed and approved by the Institutional Review Board (IRB), the University of North Carolina at Chapel Hill, NC, with reliance on the IRB at Wayne State University in Detroit, MI where the custodian of the data (PI: L. Penner) is faculty.

Participants

In the primary study, children and their primary caregivers (hereafter "parents") were eligible if the children were: 1) between 3 and 12 years old at study entry, 2) undergoing cancer therapy, and 3) experiencing regular port starts, LPs, and/or BMAs for the purposes of evaluating their response to cancer therapy and, in the case of port starts, to establish venous access through which pharmacological agents could be administered. One-hundred fifty-six children and their parents were enrolled in the primary study. Only children and their parents who provided data at baseline (T_1) and at least two of three port starts (T_2, T_3, T_4) were included in the secondary analysis. Children and parents were excluded if: 1) the child did not undergo port starts, 2) the port starts were combined with LPs or BMAs, or 3) or the port start was accomplished in < 3 minutes. Consequently, data from 43 children and their parents (one parent per child) were subjected to secondary analysis, including data from 25 children with two video-recorded port starts and data from 18 children with three video-recorded port starts, resulting in 104 video-recordings of port starts coded for secondary analysis (Figure 4.1).

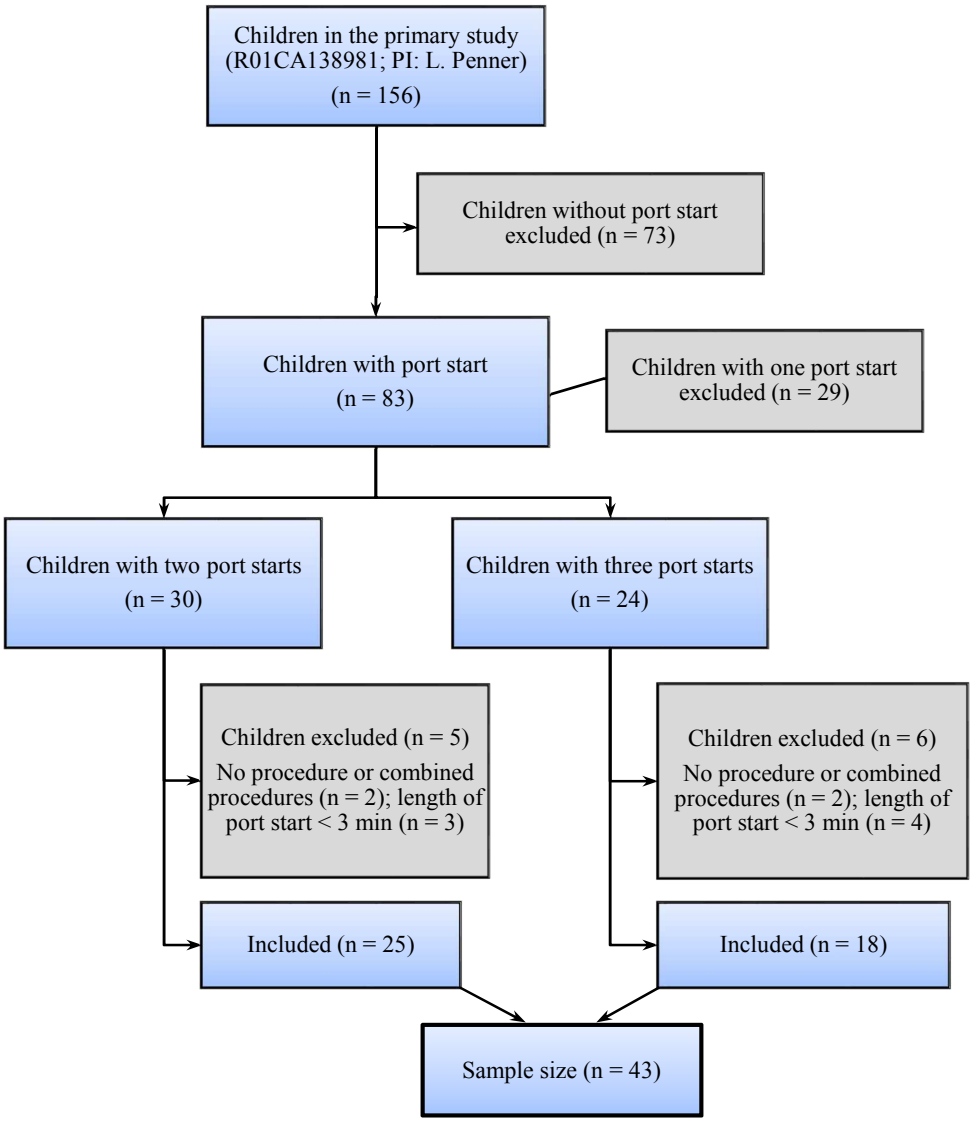


Figure 4.1 Flow diagram for the sample selection.

Measures

Study variables, their measures, reporter and collection time points are shown in Table 4.1.

Table 4.1. Study Measures

Variable	Measure	Reporter	Time
Parent demographics	Gender, ethnicity, education, economic status	Parent	T_1
Child demographics, cancer information	Age, gender, time since the treatment, total number of procedures since diagnosis	Parent, medical chart	T_1
Parent interaction behaviors	P-CaReSS (Bai et al., unpublished)	Trained coder	T_2, T_3, T_4 (pre, during, post)
Child verbal and behavioral distress	K-CCD (Harper et al., unpublished)	Trained coder	T_2, T_3, T_4 (pre, during, post)
Parent distress, child distress	Revised Wong-Baker Faces Scale (Wong & Baker, 1988; Peterson et al., 2014)	Parent, medical staff, child, trained observer	T_2, T_3, T_4 (post)
Child cooperation	Child Cooperation Scale (Peterson et al., 2014)	Parent, medical staff, trained observer	T_2, T_3, T_4 (post)

Note: K-CCD = Karmanos Child Coping and Distress Scale; P-CaReSS = Parent Caring Response Scoring System; T_1 = Baseline data collection without video recording; T_2 = 1st video recording of port start; T_3 = 2nd video recording of port start; T_4 = 3rd video recording of port start. Pre = pre-port start; during = during port start; post = post-port start.

Parent Caring Response Scoring System (P-CaReSS). The P-CaReSS was used to assess parent interaction behaviors towards their child during cancer-related port starts. The scoring system is comprised of 18 observational codes that describe parent verbal, nonverbal, and emotional indicators. Parent verbal behaviors were coded as presence or absence; onset and offset of nonverbal behavior were coded if the behavior occurs; and the emotional indicator is used to score the study session globally as having been characterized by positive, neutral or negative emotions. Parent behaviors were grouped into six domains derived from Swanson's Theory of Caring (e.g., Knowing, Being with, Doing for, Enabling, Maintaining belief, and one empirically derived domain (e.g., Non-caring). The P-CaReSS showed good inter-rater reliability (IRR) with percent agreement > 0.80 for each domain and the P-CaReSS overall.

Karmanos Child Coping and Distress Scale (K-CCD). Harper and colleagues (unpublished) developed the K-CCD to quantify a child's coping and distress behaviors during cancer-related port starts. The distress subscale was used to code the child's verbal and behavioral distress pre-, during, and post-port start in this study. This distress subscale has

acceptable inter-rater reliability with an average percent agreement of 78% between two coders (Personal communication with Dr. Harper).

Revised Wong-Baker Faces Scale. This revised scale was used to assess both parent distress and child distress during the port starts. The scale consists of six faces with rating anchors from "no pain/distress at all" (1) to "the worst pain/distress" (6) (Wong & Baker, 1988). Parent distress during port start was rated by the parent, a medical staff member and a trained observer; child distress during port start was rated by the same raters as well as the child. In a published study based on the same data set, this scale had good reliability as indicated by correlation coefficients ranging from $r = 0.57$ to $r = 0.72$ between parent, medical staff, child and trained observer ratings (Peterson et al., 2014).

Child Cooperation Scale. This scale is a one-item global rating to assess children's cooperation during cancer painful procedures, with rating anchors from "totally uncooperative" (1) to "totally cooperative" (7). In a published study based on the same data set, this scale had good reliability as indicated by correlation coefficients ranging from $r = 0.51$ to $r = 0.72$ between parent, medical staff and trained observer ratings (Peterson et al., 2014).

Coder Training

The first author and one trained research assistant (RA) coded the recorded videos under the supervision of two research scientists from Wayne State University, Detroit, MI. Both coders received training to code the video data by the P-CaReSS and K-CCD using the StudioCode© software (StudioCode Business Group, Australia). Five videos from the primary study were randomly selected to train the coders. Both coders met daily to resolve coding disagreements during the training period. The RA was considered sufficiently trained after she met a percent agreement of 0.8 with the first author (Sharpe & Koperwas, 2003). Lastly, 11 videos were used

to test the IRR between both coders, resulting in an average percent agreement above 80% between two coders for both observational measures. The videos used for coder training and instrument testing were excluded from this secondary analysis.

Coding Process

Each video of a port start was divided into three phases (i.e., pre-, during, and post-procedure) according to Cline et al.'s (2006) work. Pre-port start phase was defined as the time period between the start of video and the nurse's immediate preparation for the port start (e.g., child is lifted onto the bed or child's port is uncovered). The phase of during port start was defined as the time between the initiation of immediate preparation for the port start and the completion of port start (e.g., child's clothing is placed so that it covers the child's port). Post-port start phase was defined as the time between the end of the procedure phase and the end of video. Video segments (or "thin slices") such as 30 s or 5 min rather than the whole videos can be used to study interactions during painful medical procedures (Chorney, Tan, & Kain, 2013; Henry & Eggly, 2013). The thin slice method has been shown to increase data coding efficiency with reliability in interaction studies (Ambady, Bernieri, & Richeson, 2000; Henry & Eggly, 2013).

In the current study, three 3-5 minute slices, one for each phase described above were coded for each video, including 1) the first 5 min immediately before the start of port start, 2) a 3-5 min slice during port start (when the child was distressed or not distressed), and 3) an additional up to 5 min slice after completing the port starts. The first author prepared the slices of each video before data coding. A total of 104 videos were randomly assigned to two coders. Each coder viewed the video in full once and then coded parent interaction behaviors (P-CaReSS) and child distress (K-CCD) in multiple passes. Both coders were asked to record the onset times

for parent verbal interaction behaviors in the P-CaReSS and child verbal distress in the K-CCD; the onset and offset times were recorded for parent nonverbal interaction behaviors and emotional behavior in the P-CaReSS, and child behavioral distress in the K-CCD. The coders coded the videos independently. Questions regarding the coding process were discussed on a weekly basis.

Statistical Analysis

The statistical analysis was conducted using SAS version 9.4 (SAS Institute Inc., Cary, NC). The statistical coding is in Appendix 4.1. Prior to conducting analysis to address the specific aims, mean substitution was used for the sporadic missing data (≤ 1% of all items). Descriptive statistics were used to portray sample demographic characteristics and study variables. Means (standard deviation [SD]) were estimated for the data with approximately normal distributions, otherwise medians (interquartile range [IQR]) were estimated. Number (%) was used to present categorical data.

Study Aim 1: Due to the small sample size and the non-normal distribution of parent interaction behaviors, we simplified the multiple correlations between study variables. Therefore, mixed modeling with generalized estimating equations (GEE) was chosen to analyze the percentage change ($\%_{during} - \%_{pre}$) in parent with interaction behaviors (coded as "occurrence" or "non-occurrence") from T_2 to T_4. Pairwise comparisons were conducted among T_2, T_3, and T_4. Due to the low incidence of parent interaction behaviors in phases 1 (pre-) and 3 (post-) of the port start procedure, parent interaction behaviors for the three phases of port starts were combined. Then, the Friedman's test was performed to explore the median differences in parent interaction behaviors (i.e., frequency of parent behaviors) from T_2 to T_4.

Study Aim 2: In terms of the small sample size and the non-normal distribution of parent behavioral interactions and parent and child indicators of well-being, mixed modeling with GEE was used to test the associations between domains of parent interaction behaviors (assessed by the P-CaReSS) and the indicators of well-being–levels of parent distress, child distress, and child cooperation. First, parent distress (rated by parent, medical staff, and observer), child distress (rated by parent, medical staff, observer, and child), and child cooperation (rated by parent, medical staff, and observer) were recoded as 0 or 1 based on value close to median percentage (i.e., values within less than 50% were coded as "0" and others were coded as "1"). Based on each estimate and its 95% confidence intervals (CIs) in the mixed model, an odds ratio (OR) with its 95% CIs was calculated for each relationship analysis. In this study, OR = 1 suggests that parent interaction behaviors (domains) did not affect the occurrence of the indicators of parent or child well-being during port starts; OR > 1 suggests that parent interaction behaviors (domains) were associated with increased occurrence of the indicators of parent or child well-being during port starts; and OR < 1 suggests that parent interaction behaviors (domains) were associated with decreased occurrence of the indicator of parent or child well-being during port starts.

Study Aim 3: Time-window sequential analysis was performed to investigate whether the presence of a particular parent interaction behavior (i.e., given code) increases or decreases the probability of the occurrence of another behavior (i.e., target code) within a particular temporal window, which was set between 3s and 5s in previous studies (Chorney, Garcia, Berlin, Bakeman, & Kain, 2010). A conservative time-window of within 5s was used in this study. First, time-window sequential analysis was conducted at the individual dyad level and Yule's Q score was computed to present how parent interaction behaviors precede or follow child verbal and

behavioral distress within a 5-second time window. Yule's Q score ranges from −1 to 1, like the Pearson product-moment correlation, with the strength of negative correlations increasing as the score approaches −1 and the strength of positive correlations increasing as the score approaches 1 (Chorney et al., 2010; Chorney, Tan, & Kain, 2013). Second, mean Yule's Q values were estimated for the whole sample and a binomial test was conducted to examine whether the distribution of Yule's Q score values differed significantly from the distribution to be expected based on chance. Two sets of sequential analysis were performed by the General Sequential Querier Program (GSEQ) (Bakeman & Quera, 1995). The first set examined whether children were less likely to display verbal and behavioral distress within 5s after parent interaction behaviors than at any other time. The second examined parent interaction behaviors during children's verbal and behavioral distress.

Results

Demographics and Cancer-Related Information

Demographic information for study participants is shown in Table 4.2. The children's cancer-related information is shown in Table 4.3. Information about the duration of the children's port starts is shown in Table 4.4. Almost all (93-95%) of the children had received a mixture of local anesthetics—prilocaine and lidocaine (EMLA)—applied to the skin over their port at least 30 minutes before their port start. The reasons of about 5% children not receiving the EMLA are rejections by children, forgetting using it by parents, and never used it before. The mean duration of the port starts were 6.08 min (SD = 2.21), 6.54 min (SD = 2.74), and 6.55 min (SD = 2.88) at T_2, T_3, and T_4, respectively.

Table 4.2. Participant Demographic Information

Variable	Mean (SD)	Range	n (%)
Child			
Age, year	6.4 (3.0)	3-12	
Gender			
Female			17 (39.5)
Male			26 (60.5)
Race			
White			31 (72.1)
Black/African American			8 (18.6)
Other			4 (9.3)
Parent			
Age, year	34.4 (7.1)	20-54	
Gender			
Female			34 (79.1)
Male			9 (20.9)
Relationship to child			
Mother			33 (76.7)
Father			9 (20.9)
Grandmother			1 (2.3)
Race			
White			32 (74.4)
Black/Africa American			7 (16.3)
Other			4 (9.3)
Marital Status			
Married or domestic partnered			28 (65.1)
Separated, divorced, or widowed			10 (23.2)
Never married			5 (11.6)
Education			
Middle school			2 (4.7)
Some or completed high school			10 (23.3)
Some years of college or completed Bachelor's degree			24 (55.8)
Master's degree or above			7 (16.3)
Household income			
Less than $10, 000			8 (18.6)
$10,000 − $19, 999			7 (16.3)
$20,000 − $39, 999			6 (14.0)
$40,000 − $59, 999			3 (7.0)
$60,000 − $100, 000			10 (23.3)
More than $100, 000			6 (14.0)
Employment status			
Unemployed			20 (46.5)
Part-time			8 (18.7)
Full-time			14 (32.6)
Retired			1 (2.3)
Parent in room during port starts			
Primary caregiver			26 (60.5)
Both caregivers			17 (39.5)

Note: SD = standard deviation

Table 4.3. Child Cancer-Related Information

Variable	Mean (SD)	Range	n (%)
Diagnosis			
Acute Lymphocytic Leukemia			28 (65.1)
Wilms' Tumor			6 (14.0)
Non-Hodgkin's Lymphoma			2 (4.7)
Hodgkin's Lymphoma			1 (2.3)
Sarcoma (unspecified)			2 (4.7)
Other cancer			4 (9.2)
Cancer therapy			
Surgery alone			4 (9.3)
Chemotherapy alone			17 (39.5)
Chemotherapy and surgery			11 (25.6)
Chemotherapy, surgery and radiotherapy			2 (4.7)
Chemotherapy, surgery, radiotherapy and other			2 (4.7)
Others			1 (2.3)
LPs			
Yes			34 (79.1)
No			9 (20.9)
Number of LPs in past two months	3 (3)	0-10	
Number of LPs since diagnosis	7 (6)	0-30	
BMAs			
Yes			33 (76.7)
No			9 (20.9)
Number of BMAs in past two months	1 (1)	0-6	
Number of BMAs since diagnosis	2 (2)	0-9	
Number of port starts in past 2 months	10 (8)	0-30	
Other illness in past 2 months			
Yes			22 (51.2)
No			21 (48.8)

Note: BMAs = bone marrow aspirations; LPs = lumbar punctures; SD = standard deviation

Table 4.4. Length of Pre–, During, and Post–Port Starts at T_2, T_3 and T_4

Variables	Mean (SD), min		
	T_2 (n = 37)	T_3 (n = 37)	T_4 (n = 30)
Total length of port start	53.33 (32.20)	50.48 (36.45)	40.69 (26.63)
Length of pre-port start	35.31 (26.62	34.08 (33.47)	26.50 (25.21)
Length of port start	6.08 (2.21)	6.54 (2.74)	6.55 (2.88)
Length of post port start	11.94 (14.62)	9.09 (11.86)	7.65 (10.72)
Use of EMLA, n (%)			
Yes	35 (0.95)	35 (0.95)	28 (0.93)
No	2 (0.05)	2 (0.05)	2 (0.07)

Note: EMLA = eutectic mixture of local anesthetics−prilocaine and lidocaine; SD = standard deviation; T_2 = 1st recorded video of port start; T_3 = 2nd recorded video of port start; T_4 = 3rd recorded video of port start

Indicators of Parent and Child Well-Being: Parent Distress, Child Distress, and Child Cooperation

Immediately after each port start, parent, medical staff, and a trained observer reported levels of parent distress, child distress, and child cooperation throughout the procedure. Children also reported their distress level at regular intervals throughout the procedure. Table 4.5 shows mean scores of these indicators. Parents reported a higher mean score of parent distress than those reported by medical staff and observers; medical staff reported the lowest mean score of parent distress. Parents reported a higher mean score of child distress than those reported by medical staff and observers; medical staff consistently reported the lowest mean score for child distress. In addition, medical staff reported a higher mean score of child cooperation compared with those scores from parents and observers, and no consistent pattern was found in the lowest mean scores of child cooperation among three raters. Due to inconsistent patterns of change in rating by the various raters (Table 4.5), all the ratings were used to study the relationships between parent interaction behaviors and parent distress, child distress, and child cooperation.

Table 4.5. Parent Distress, Child Distress and Child Cooperation During Port Starts at T_2, T_3 and T_4

	T_2		T_3		T_4	
Variable	**n**	**Mean (SD)**	**n**	**Mean (SD)**	**n**	**Mean (SD)**
Parent−report parent distress	42	**2.55 (1.47)**	40	**2.40 (1.37)**	35	**2.20 (1.13)**
Medial staff−report parent distress	38	1.95 (1.09)	37	1.76 (0.89)	34	1.59 (0.78)
Trained Observer−report parent distress	42	1.63 (0.95)	40	1.84 (1.13)	35	1.68 (0.76)
Parent−report child distress	41	**3.27 (1.84)**	39	3.26 (1.94)	33	**2.91 (1.79)**
Medical staff−report child distress	42	2.74 (1.52)	39	2.74 (1.68)	34	2.38 (1.52)
Trained Observer−report child distress	43	2.93 (2.01)	40	3.46 (2.18)	35	2.75 (1.75)
Child−report child distress	34	2.68 (2.13)	33	**3.52 (2.17)**	28	2.79 (2.04)
Parent−report child cooperation	42	**5.62 (1.90)**	40	5.58 (2.00)	35	5.63 (1.82)
Medical staff−report child cooperation	42	5.45 (2.11)	39	**5.64 (1.99)**	34	**6.24 (1.58)**
Trained Observer−report child cooperation	43	5.60 (2.08)	40	5.14 (2.25)	35	6.18 (1.34)

Note: The highest score was **bolded**; the lowest score was underlined.

Study Aim 1: Change in Parent Interaction Behaviors over the Repeated Port Starts

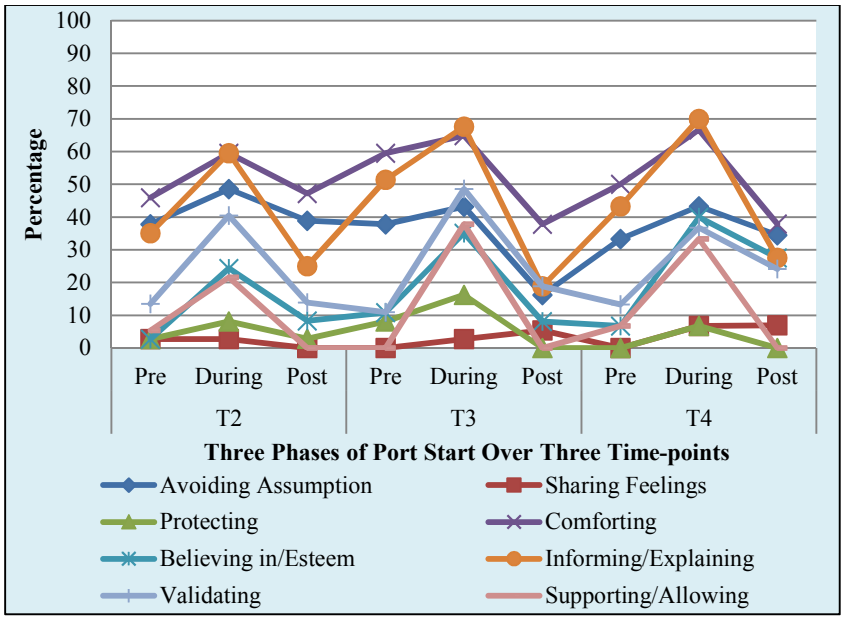
Parent interaction behaviors over the three phases of a port start. Table 4.6 describes the percentage of parent interaction behaviors over the three phases of port start as previously defined. Throughout the port start, more than 50% of parents displayed verbal comforting, informing and explaining behaviors, close proximity to their child and nonverbal supporting and allowing behaviors. Regarding parent non-caring behaviors, parents displayed more unavailability but fewer criticizing and apologizing behaviors.

Figure 4.2 shows the trend of parent interaction behaviors pre-, during, and post-port start over time, including parent verbal and nonverbal caring behaviors, non-caring behaviors, and emotional behavior. As shown in Figure 4.2.1, a greater percentage of parents used verbal caring behaviors in phase 2 (during port start) as compared to in phase 1 (pre-port start) or phase 3 (post-port start). As shown in Figure 4.2.2, the percentage of parents exhibiting nonverbal caring behaviors decreased over the three phases. As shown in Figure 4.2.3, more parents displayed verbal non-caring behaviors, such as criticizing and apologizing in phase 2 as compared to in phases 1 or 3, and fewer parents used nonverbal non-caring behaviors in phase 2 as compared to in phases 1 or 3. As shown in Figure 4.2.4, more parents displayed positive (i.e., caring) emotions in phase 2 as compared to phases 1 or 3. The percentage of parents exhibiting negative emotions remained stable over the three phases of port start.

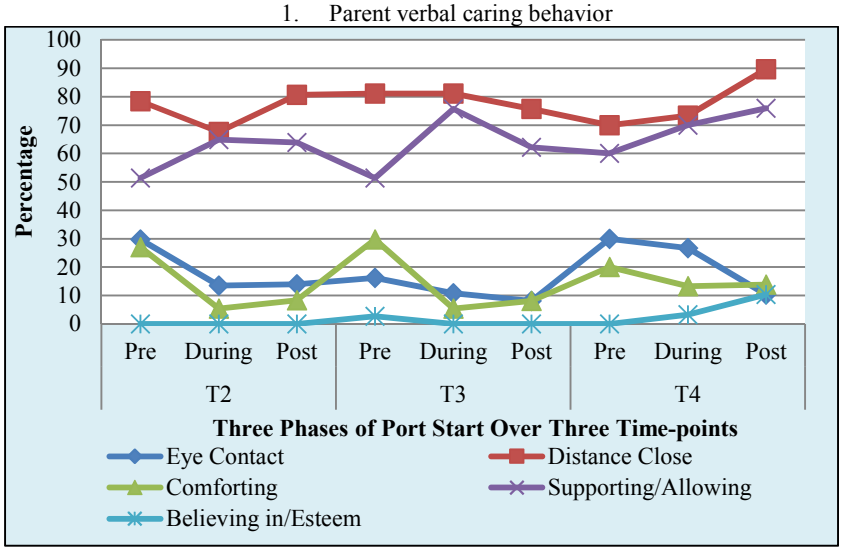
Table 4.6. Parent Interaction Behaviors During the Three Phases of the Port Start Procedure Over Time, n (%)

	T_2 (n = 37)			T_3 (n = 37)			T_4 (n = 30)		
Parent Behavior	**Pre**	**During**	**Post***	**Pre**	**During**	**Post**	**Pre**	**During**	**Post****
Knowing									
Avoiding Assumption	14 (37.8)	18 (48.6)	15 (38.9)	14 (37.8)	16 (43.2)	6 (16.2)	10 (33.3)	17 (43.3)	10 (34.5)
Being with									
Sharing Feelings	1 (2.7)	1 (2.7)	0	0	1 (2.7)	2 (5.4)	0	2 (6.7)	2 (6.9)
Doing for									
Protecting	1 (2.7)	3 (8.1)	1 (2.8)	3 (8.1)	6 (16.2)	0	0	2 (6.7)	0
Comforting	17 (45.9)	22 (59.5)	17 (47.2)	22 (59.5)	24 (64.9)	14 (37.8)	15 (50.0)	20 (66.7)	11 (37.9)
Maintaining Belief									
Believing in/Esteem	1 (2.7)	9 (24.3)	3 (8.3)	4 (10.8)	13 (35.1	3 (8.1)	2 (6.7)	12 (40.0)	8 (27.6)
Enabling									
Informing/Explaining	13 (35.1)	22 (59.5)	9 (25)	19 (51.4)	25 (67.6)	7 (18.9)	13 (43.3)	21 (70.0)	8 (27.6)
Validating	5 (13.5)	15 (40.5)	5 (13.9)	7 (10.9)	18 (48.6)	7 (18.9)	4 (13.3)	11 (36.7)	7 (24.1)
Supporting/Allowing	2 (5.4)	8 (21.6)	0	0	14 (37.8	0	2 (6.7)	7 (33.3)	0
Non-Caring									
Criticizing	3 (8.1)	4 (10.8)	1 (2.8)	3 (8.1)	4 (10.8)	1 (2.7)	5 (16.7)	4 (13.3)	0
Apologizing	1 (2.7)	1 (2.7)	2 (5.6)	2 (5.4)	3 (8.1)	1 (2.7)	0	1 (3.3)	0
Burdens/Intrusive Questions	4 (10.8)	7 (18.9)	3 (8.3)	6 (26.2)	5 (13.5)	3 (8.1)	1 (3.3)	6 (20.0)	0
Being with									
Eye Contact	11 (29.7)	5 (13.5)	5 (13.9)	6 (16.2)	4 (10.8)	3 (8.1)	9 (30.0)	8 (26.7)	3 (10.3)
Distance Close Enough to Touch	29 (78.4)	25 (67.6)	29 (80.6)	30 (81.1)	30 (81.1)	28 (75.7)	21 (70.0)	22 (73.3)	26 (89.7)
Doing for									
Nonverbal Comforting	10 (27)	2 (5.4)	3 (8.3)	11 (29.7)	2 (5.4)	3 (8.1)	6 (20.0)	4 (13.3)	4 (13.8)
Enabling									
Nonverbal Supporting/Allowing	19 (51.4)	24 (64.9)	23 (63.9)	19 (51.4)	28 (75.7)	23 (62.2)	18 (60.0)	21 (70.0)	22 (75.9)
Maintaining Belief									
Nonverbal Believing in/Esteem	0	0	0	1 (2.7)	0	0	0	1 (3.3)	3 (10.3)
Non-Caring									
Less Availability	34 (91.9)	20 (54.1)	23 (63.9)	27 (73)	22 (59.5)	24 (64.9)	24 (80.0)	19 (63.3)	22 (75.9)
Emotional Behavior									
Caring (Positive)	17 (46.0)	24 (64.9)	21 (58.3)	19 51.4)	27 (73.0)	21 (56.8)	20 (66.7)	23 (73.7)	20 (69.0)
Neutral	16 (43.2)	10 (27.0)	13 (36.1)	15 (40.5)	8 (21.6)	13 (35.1)	7 (23.3)	5 (16.7)	7 (24.1)
Non-Caring (Negative)	4 (10.8)	3 (8.1)	2 (5.6)	3 (8.1)	2 (5.4)	3 (8.1)	3 (10.0)	2 (6.6)	2 (6.9)

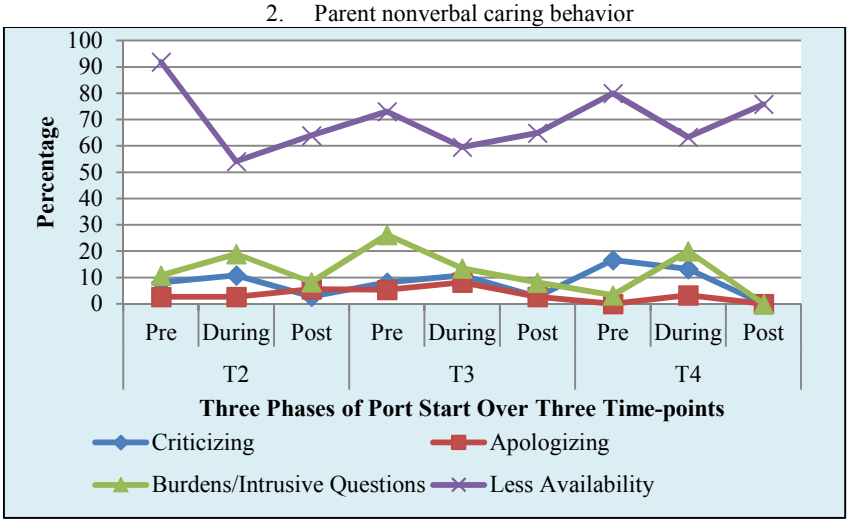
Note: * n = 36; ** n = 29



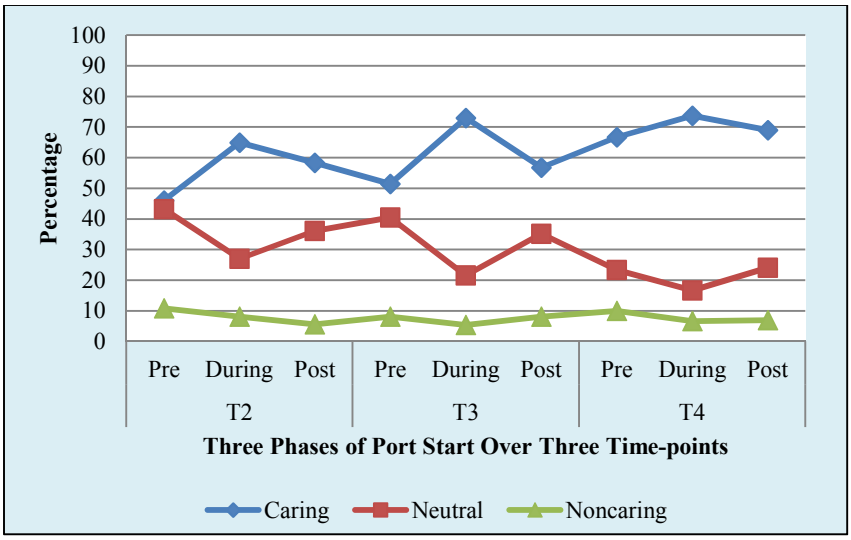
1. Parent verbal caring behavior



2. Parent nonverbal caring behavior



3. Parent non-caring behavior



4. Parent emotional behavior

Figure 4.2. Trends in parent interaction behaviors during the three port start phases over time.

Change in parent interaction behaviors during the three port start phases over time. Mixed modeling with GEE was used to analyze percent change in parent interaction behaviors ($\%_{during} - \%_{pre}$) over time. No significant difference was found with respect to the majority of parent verbal interaction behaviors (Table 4.7). Significant differences were found between T_2 and T_4 in the following items: eye contact ($\beta = -1.05$, $p = 0.02$), distance close enough to touch ($\beta = -0.81$, $p = 0.03$), nonverbal comforting ($\beta = -1.34$, $p = 0.04$), and less availability ($\beta = -0.92$, $p = 0.036$), indicating that more parents displayed nonverbal behaviors over time. In addition, more parents displayed burdens/intrusive questions ($\beta = -1.11$, $p = 0.03$) and nonverbal comforting ($\beta = -1.52$, $p = 0.047$) behaviors from T_3 to T_4.

Parent interaction behaviors through the complete port start over time. Due to the low occurrence of parent interaction behaviors in phases 1 (pre-port start) and 3 (post-port start), we combined all three phases to represent the "entire port start." Table 4.8 describes the percentage, median, and $25^{th}/75^{th}$ percentile for each parent interaction behavior.

Change in parent interaction behaviors during the entire port start procedure over time. Figure 4.3 shows the trend in parent interaction behaviors during the entire procedure port start over time. As shown in Figure 4.3.1, parents displayed increases in the following verbal caring behaviors over time: sharing feelings, believing in/esteem, while parents displayed decreased informing/explaining; avoiding assumption and comforting behaviors over time. As shown in Figure 4.3.2, parent nonverbal caring behaviors increased over time, including comforting, supporting/allowing, and believing in/esteem. As shown in Figure 4.3.3, parent non-caring verbal and non-verbal behaviors decreased over time, including apologizing, burdens/intrusive questions, and less availability. When Friedman's test was used to examine differences between the median scores, parent interaction behaviors were not found to change significantly from T_2 to T_4 (Table 4.8).

Table 4.7. Pairwise Comparisons of Parent Interaction Behaviors from T_2 to T_4 Controlling for Pre-Procedure Behaviors

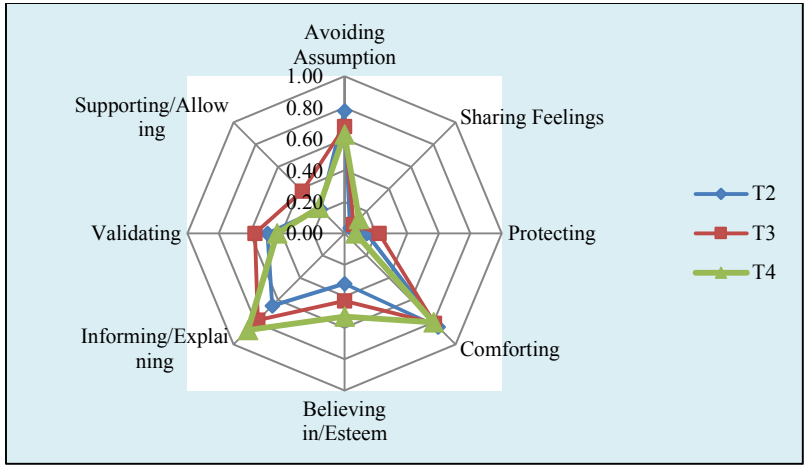
	LS Means ($\%_{during} - \%_{pre}$)			T_2 vs. T_3		T_2 vs. T_4		T_3 vs. T_4	
Parent Behavior	**T_2**	**T_3**	**T_4**	**Estimate***	**p**	**Estimate***	**p**	**Estimate***	**p**
Knowing									
Avoiding Assumption	0.29	0.08	0.41	0.21	0.63	-0.13	0.78	-0.33	0.42
Being with									
Sharing Feelings	-2.83	-2.04	-1.2	-0.79	0.6	-1.63	0.26	-0.84	0.38
Doing for									
Protecting	-1.45	-1.08	-1.14	-0.37	0.67	-0.31	0.6	0.05	0.94
Comforting	0.77	0.84	1.23	-0.7	0.85	-0.46	0.34	-0.39	0.36
Maintaining Belief									
Believing in/Esteem	-0.35	-0.09	0.31	-0.26	0.54	-0.66	0.17	-0.4	0.43
Enabling									
Informing/Explaining	0.98	1.07	1.48	-0.09	0.85	-0.5	0.37	-0.41	0.51
Validating	0.22	0.47	0.23	-0.25	0.46	-0.01	0.98	0.24	0.5
Supporting/Allowing	NA	NA	NA	NA	NA	NA	NA	NA	NA
Non-Caring									
Criticizing	-1.32	-1.32	-1.16	-0.01	0.99	-0.16	0.83	-0.15	0.78
Apologizing	-2.38	-1.8	-1.52	-0.58	0.63	-0.85	0.22	-0.27	0.74
Burdens/Intrusive Questions	-0.87	-1.45	-0.34	0.58	0.41	-0.53	0.32	-1.11	**0.03***
Being with									
Eye Contact	-1.4	-1.2	-0.35	-0.2	0.73	-1.05	**0.02***	-0.84	0.16
Distance Close Enough to Touch	1.01	1.78	1.82	-0.77	0.07	-0.81	**0.03***	-0.04	0.93
Doing for									
Nonverbal Comforting	-2.32	-2.49	-0.97	0.17	0.81	-1.34	**0.04***	-1.52	**0.047***
Enabling									
Nonverbal Supporting/Allowing	1.05	1.57	1.41	-0.52	0.14	-0.36	0.47	0.16	0.75
Maintaining Belief									
Nonverbal Believing in/Esteem	NA	NA	NA	NA	NA	NA	NA	NA	NA
Non-Caring									
Less Availability	0.22	0.89	1.15	-0.67	0.097	-0.92	**0.036***	-0.26	0.54

Note: Estimate* = Estimate of differences of time least squares means; NA = not applicable;
* $p < 0.05$

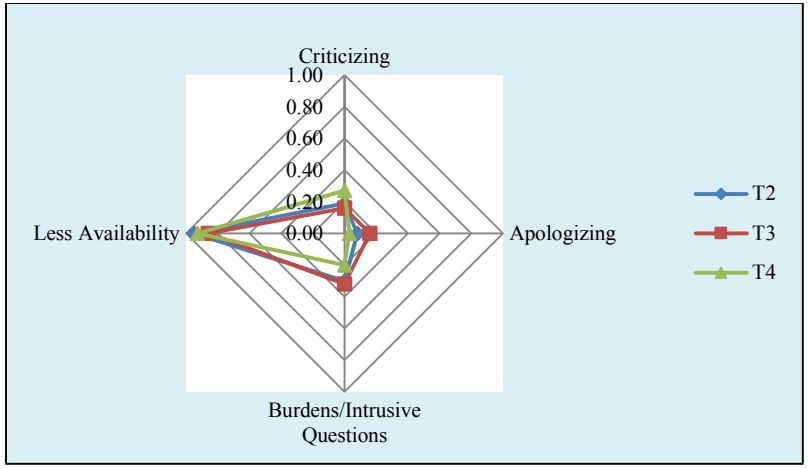
Table 4.8. Change in Parent Interaction Behaviors Over Time

Parent Behavior	T_2 (n = 37)			T_3 (n = 37)			T_4 (n = 30)			Friedman's Test p
	n (%)	Median /h	25th/75th Percentile	n (%)	Median /h	25th/75th Percentile	n (%)	Median /h	25th/75th Percentile	
Knowing										
Avoiding Assumption	29 (0.78)	12.00	5.05/19.06	25 (0.68)	8.35	5.17/17.05	19 (0.63)	12.00	6.26/22.96	0.50
Being with										
Sharing Feelings	2 (0.05)	10.12	8.25/12.00	3 (0.08)	4.00	4.00/4.45	4 (0.13)	5.34	4.41/7.36	0.38
Doing for										
Protecting	5 (0.14)	6.57	4.69/8.88	8 (0.22)	4.84	4.02/7.47	2 (0.07)	10.09	4.13/16.05	0.22
Comforting	31 (0.84)	16.61	8.00/40.10	30 (0.81)	37.92	12.93/57.24	24 (0.80)	41.91	20.17/65.53	0.78
Maintaining Belief										
Believing in/Esteem	12 (0.32)	7.38	4.40/9.76	16 (0.43)	10.95	4.07/14.95	16 (0.53)	12.66	8.35/19.43	0.06
Enabling										
Informing/Explaining	24 (0.65)	17.00	4.85/42.40	29 (0.78)	21.98	9.03/55.06	26 (0.87)	17.45	8.11/47.40	0.13
Validating	18 (0.49)	13.69	7.20/22.88	21 (0.57)	17.63	9.88/28.70	13 (0.43)	22.73	8.36/29.80	0.29
Supporting/Allowing	8 (0.22)	10.60	5.26/22.29	14 (0.38)	8.00	4.33/10.76	7 (0.23)	12.05	8.00/26.37	0.47
Non-Caring										
Criticizing	7 (0.19)	5.45	4.51/8.99	6 (0.16)	9.63	4.34/16.57	8 (0.27)	8.66	4.86/21.23	0.60
Apologizing	3 (0.08)	4.51	4.34/8.51	6 (0.16)	5.09	4.20/11.26	1 (0.03)	4.70	4.70/4.70	0.12
Burdens/Intrusive Questions	11 (0.30)	8.69	4.38/12.37	12 (0.32)	7.25	4.32/11.67	6 (0.20)	14.77	9.20/21.20	0.32
Being with										
Eye Contact	14 (0.38)	0.55	0.44/1.37	12 (0.32)	0.48	0.20/0.78	14 (0.47)	1.20	0.71/2.88	0.31
Distance Close Enough to Touch	35 (0.95)	40.00	9.67/53.63	33 (0.89)	49.25	25.37/58.30	29 (0.97)	39.34	6.33/52.34	0.49
Doing for										
Nonverbal Comforting	11 (0.30)	1.80	0.51/7.44	14 (0.38)	2.52	0.79/4.46	12 (0.40)	0.39	0.21/2.27	0.34
Enabling										
Nonverbal Supporting/Allowing	28 (0.76)	16.32	8.75/28.62	31 (0.84)	19.40	8.57/42.05	27 (0.90)	22.06	5.01/32.01	0.34
Maintaining Belief										
Nonverbal Believing in/Esteem	0 (0)	NA	NA	1 (0.03)	0.07	0.07/0.07	4 (0.13)	0.14	0.13/0.17	0.08
Non-Caring										
Less Availability	35 (0.95)	21.06	10.07/51.16	32 (0.86)	26.18	8.89/50.02	28 (0.93)	23.24	6.93/52.64	0.91

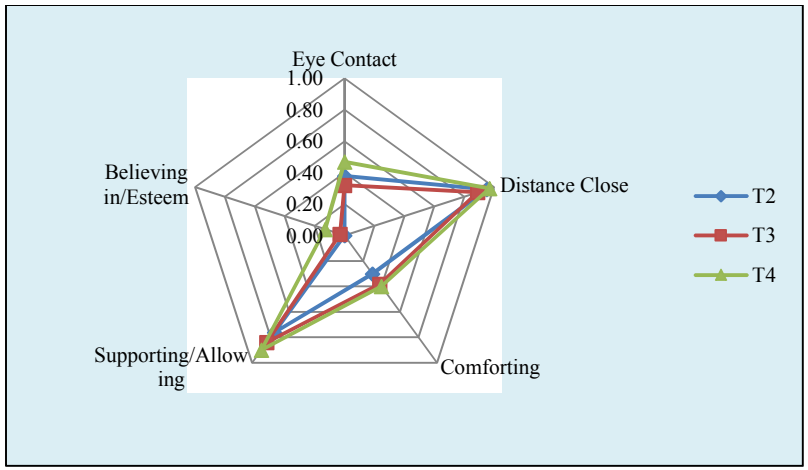
Note: NA = not applicable



1. Verbal caring behaviors



3. Non-caring behaviors



2. Nonverbal caring behaviors

Figure 4.3. Trends of parent interaction behaviors during the complete procedure over time.

Study Aim 2: Relations Between Parent Interaction Behaviors and Various Raters-Report Indicators of Parent and Child Well-Being

Relationships between parent interaction behaviors and indicators of parent and child well-being. As shown in Table 4.9, parent interaction behaviors were positively correlated with parent distress ratings by at least two raters, including informing/explaining (ORs 1.02, $p < 0.05$), validating (ORs 1.05, $p < 0.05$), and nonverbal supporting/allowing (ORs 1.05, $p < 0.05$). Less availability of the parent was negatively correlated with parent distress ratings by at least two raters (ORs 0.95~0.98, $p < 0.05$).

As shown in Table 4.10, parent interaction behaviors were positively correlated with child distress rated by at least two raters, including informing/explaining (ORs 1.02, $p < 0.05$), validating (ORs 1.05~1.13, all $p < 0.01$), burdens/intrusive questions (ORs 1.07, $p < 0.05$), distance close enough to touch (ORs 1.02~1.03, $p < 0.05$), and nonverbal supporting/allowing (ORs 1.04~1.05, $p < 0.05$). Less parent availability was negatively correlated with child distress ratings by at least two raters (ORs 0.97~0.98, $p < 0.05$).

As shown in Table 4.11, parent interaction behaviors were negatively correlated with child cooperation ratings by at least two raters, including protecting (ORs 0.84~0.85, $p < 0.05$), informing/explaining (ORs 0.97~0.98, $p < 0.05$), validating (ORs 0.87~0.9, $p < 0.01$), burdens/intrusive questions (ORs 0.88~0.92, $p < 0.01$), distance close enough to touch (ORs 0.96~0.98, $p < 0.05$), and nonverbal supporting/allowing (ORs 0.94~0.96, $p < 0.05$). Parent less availability was positively correlated with child cooperation reported by at least two raters (ORs 1.03~1.04, $p < 0.01$).

Relationships between domains of parent interaction behaviors and indicators of parent and child well-being. Table 4.12 shows the correlations between domains of parent interaction behaviors and parent distress ratings by various raters. Tables 4.13 and 4.14 report the

relationships between domains of parent interaction behaviors and ratings of child distress and child cooperation by various raters.

Table 4.9. Correlations between Parent Interaction Behaviors and Parent Distress Ratings by Various Raters

	Parent-Report			Medical Staff-Report			Observer-Report		
Parent Behavior	**Estimate**	**OR (95% CI)**	**p**	**Estimate**	**OR (95% CI)**	**p**	**Estimate**	**OR (95% CI)**	**p**
Knowing									
Avoiding Assumption	0.03	—	0.2	0.001	—	0.92	0.02	—	0.26
Being with									
Sharing Feelings	0.09	—	0.41	-0.03	—	0.77	0.14	—	0.23
Doing for									
Protecting	0.09	—	0.13	0.002	—	0.98	0.2	**1.22 (1.05, 1.42)**	**0.01**
Comforting	0.003	—	0.58	0.002	—	0.65	-0.004	—	0.4
Maintaining Belief									
Believing in/Esteem	0.02	—	0.59	0.06	**1.06 (1.01, 1.13)**	**0.03**	-0.001	—	0.97
Enabling									
Informing/Explaining	0.02	**1.02 (1, 1.04)**	**0.047**	0.02	**1.02 (1, 1.03)**	**0.05**	0.001	—	0.85
Validating	0.05	**1.05 (1.01, 1.09)**	**0.01**	0.05	**1.05 (1.01, 1.09)**	**0.01**	0.03	—	0.1
Supporting/Allowing	0.07	—	0.096	0.07	—	0.14	0.03	—	0.3
Non-Caring									
Criticizing	0.1	**1.11 (1.02, 1.21)**	**0.02**	0.05	—	0.25	-0.01	—	0.75
Apologizing	-0.04	—	0.64	-0.05	—	0.6	-0.05	—	0.57
Burdens/Intrusive Questions	0.01	—	0.4	0.05	**1.22 (1.05, 1.42)**	**0.05**	0.04	—	0.13
Being with									
Eye Contact	0.01	—	0.64	-0.24	—	0.28	0.16	—	0.51
Distance Close Enough to Touch	0.01	—	0.2	0.03	**1.03 (1.01, 1.05)**	**0.004**	-0.01	—	0.44
Doing for									
Nonverbal Comforting	-0.02	—	0.74	0.04	—	0.5	-0.05	—	0.4
Enabling									
Nonverbal Supporting /Allowing	0.05	**1.05 (1, 1.09)**	**0.03**	0.05	**1.05 (1.02, 1.08)**	**0.0003**	-0.009	—	0.42
Maintaining Belief									
Nonverbal Believing in/Esteem	14.53	—	0.06	3.06	—	0.55	-17.88	**0 (0, 0.19)**	**0.03**
Non-Caring									
Less Availability	-0.02	**0.98 (0.96, 1)**	**0.02**	-0.05	**0.95 (0.93, 0.98)**	**0.0001**	0.01	—	0.43

Table 4.10. Correlations between Parent Interaction Behaviors and Child Distress Ratings by Various Raters

	Parent-Report			Medical Staff-Report			Observer-Report			Child-Report		
Parent Behavior	**Estimate**	**OR (95% CI)**	**p**	**Estimate**	**OR (95% CI)**	**p**	**Estimate**	**OR (95% CI)**	**p**	**Estimate**	**OR (95% CI)**	**p**
Knowing												
Avoiding Assumption	0.02	—	0.38	-0.001	—	0.95	0.02	—	0.19	0.04	**1.04 (1,1.07)**	**0.045**
Being with												
Sharing Feelings	-0.05	—	0.31	-0.14	—	0.21	-0.13	—	0.07	0.04	—	0.41
Doing for												
Protecting	0.13	—	0.13	0.12	—	0.11	0.18	**1.2 (1.05, 1.36)**	**0.01**	0.15	—	0.29
Comforting	-0.01	—	0.38	0.01	—	0.45	0.01	—	0.26	-0.001	—	0.91
Maintaining Belief												
Believing in/Esteem	-0.003	—	0.9	0.04	—	0.17	0.05	**1.05 (1.01, 1.11)**	**0.03**	-0.01	—	0.63
Enabling												
Informing/Explaining	0.02	—	0.07	0.02	**1.02 (1, 1.04)**	**0.03**	0.02	**1.02 (1, 1.04)**	**0.02**	0.01	—	0.25
Validating	0.11	**1.12 (1.03, 1.2)**	**0.004**	0.05	**1.05 (1.01, 1.08)**	**0.01**	0.12	**1.13 (1.05, 1.21)**	**0.002**	0.09	**1.09 (1.03, 1.15)**	**0.003**
Supporting/Allowing	0.04	—	0.34	0.02	—	0.48	0.07	**1.07 (1, 1.14)**	**0.04**	0.03	—	0.28
Non-Caring												
Criticizing	0.04	—	0.17	0.01	—	0.82	0.02	—	0.74	0.04	—	0.26
Apologizing	0.01	—	0.88	0.05	—	0.59	-0.01	—	0.89	0.11	—	0.13
Burdens/Intrusive Questions	0.07	—	0.08	0.07	**1.07 (1, 1.15)**	**0.049**	0.07	**1.07 (1.01, 1.14)**	**0.01**	0.01	—	0.39
Being with												
Eye Contact	0.54	—	0.08	0.13	—	0.41	0.22	—	0.33	0.42	—	0.07
Distance Close Enough to Touch	0.03	**1.03 (1.01, 1.04)**	**0.006**	0.02	**1.02 (1, 1.03)**	**0.05**	0.03	**1.03 (1.01, 1.05)**	**0.002**	0.02	**1.02 (1, 1.04)**	**0.02**
Doing for												
Nonverbal Comforting	-0.01	—	0.82	-0.003	—	0.96	0.11	—	0.27	0.03	—	0.54
Enabling												
Nonverbal Supporting/ Allowing	0.05	**1.05 (1.02, 1.1)**	**0.006**	0.04	**1.04 (1.01, 1.07)**	**0.02**	0.04	**1.05 (1, 1.09)**	**0.03**	0.05	**1.05 (1, 1.1)**	**0.04**
Maintaining Belief												
Nonverbal Believing in/Esteem	-0.63	—	0.84	0.81	—	0.84	-7.7	—	0.25	-1	—	0.7
Non-Caring												
Less Availability	-0.03	**0.97 (0.95, 0.99)**	**0.002**	-0.03	**0.97 (0.96, 0.99)**	**0.002**	-0.02	**0.98 (0.96, 1)**	**0.02**	-0.02	—	0.07

Table 4.11. Correlations Between Parent Interaction Behaviors and Child Cooperation Ratings by Various Raters

	Parent-Report			Medical Staff-Report			Observer-Report		
Parent Behavior	**Estimate**	**OR (95% CI)**	**p**	**Estimate**	**OR (95% CI)**	**p**	**Estimate**	**OR (95% CI)**	**p**
Knowing									
Avoiding Assumption	-0.02	—	0.23	-0.01	—	0.54	0.01	—	0.55
Being with									
Sharing Feelings	0.08	—	0.44	0.01	—	0.89	0.01	—	0.9
Doing for									
Protecting	-0.06	—	0.3	-0.18	**0.84 (0.69, 1)**	**0.049**	-0.16	**0.85 (0.76, 0.97)**	**0.01**
Comforting	-0.01	—	0.21	-0.003	—	0.66	-0.02	**0.98 (0.97, 1)**	**0.01**
Maintaining Belief									
Believing in/Esteem	-0.03	—	0.33	-0.02	—	0.43	-0.07	**0.93 (0.88, 0.98)**	**0.01**
Enabling									
Informing/Explaining	-0.02	**0.98 (0.96, 0.99)**	**0.01**	-0.02	**0.98 (0.96, 1)**	**0.01**	-0.03	**0.97 (0.94, 0.99)**	**0.02**
Validating	-0.11	**0.9 (0.84, 0.96)**	**0.001**	-0.14	**0.87 (0.82, 0.93)**	**< 0.0001**	-0.05	—	0.06
Supporting/Allowing	-0.05	—	0.24	-0.04	—	0.35	-0.02	—	0.44
Non-Caring									
Criticizing	-0.06	—	0.35	-0.04	—	0.25	-0.06	—	0.33
Apologizing	-0.1	—	0.35	-0.23	**0.79 (0.67, 0.94)**	**0.01**	0.07	—	0.45
Burdens/Intrusive Questions	-0.06	—	0.19	-0.13	**0.88 (0.79, 0.97)**	**0.008**	-0.08	**0.92 (0.87, 0.97)**	**0.004**
Being with									
Eye Contact	-0.56	—	0.06	-0.1	—	0.66	-0.17	—	0.31
Distance Close Enough to Touch	-0.04	**0.96 (0.95, 0.98)**	**0.0003**	-0.03	**0.97 (0.95, 0.99)**	**0.001**	-0.03	**0.98 (.96, 1)**	**0.02**
Doing for									
Nonverbal Comforting	-0.001	—	0.99	-0.01	—	0.87	-0.08	—	0.38
Enabling									
Nonverbal Supporting/Allowing	-0.04	**0.96 (0.93, 0.99)**	**0.008**	-0.06	**0.94 (0.9, 0.97)**	**0.001**	-0.04	**0.96 (0.93, 1)**	**0.049**
Maintaining Belief									
Nonverbal Believing in/Esteem	2.88	—	0.71	-5.28	—	0.25	-4.22	—	0.59
Non-Caring									
Less Availability	0.04	**1.04 (1.02, 1.06)**	**< 0.0001**	0.03	**1.03 (1.01, 1.05)**	**0.002**	0.03	**1.03 (1.01, 1.06)**	**0.004**

Table 4.12. Correlations Between Domains of Parent Interaction Behaviors and Parent Distress Reported by Various Raters

Parent Behavior Domain	Parent-Report			Medical Staff-Report			Observer-Report		
	Estimate	**OR (95% CI)**	**p**	**Estimate**	**OR (95% CI)**	**p**	**Estimate**	**OR (95% CI)**	**p**
Verbal Domains									
Knowing	0.03	—	0.2	0.001	—	0.92	0.02	—	0.26
Being with	0.09	—	0.41	-0.03	—	0.77	0.14	—	0.23
Doing for	0.004	—	0.5	0.002	—	0.65	-0.003	—	0.5
Maintaining Belief	0.02	—	0.59	0.06	**1.06 (1.01, 1.13)**	**0.03**	-0.001	—	0.97
Enabling	0.02	**1.02 (1.01, 1.04)**	**0.002**	0.02	**1.02 (1.01, 1.04)**	**0.004**	0.01	—	0.3
Non-Caring	0.03	—	0.14	0.04	—	0.055	0.02	—	0.19
Nonverbal Domains									
Being with	0.03	—	0.19	0.06	**1.06 (1.02, 1.11)**	**0.005**	-0.01	—	0.47
Doing for	-0.02	—	0.74	0.04	—	0.5	-0.05	—	0.4
Enabling	0.05	**1.05 (1, 1.09)**	**0.03**	0.05	**1.05 (1.02, 1.08)**	**0.0003**	-0.009	—	0.42
Maintaining Belief	14.53	—	0.06	3.06	—	0.55	-17.88	**0 (0, 0.19)**	**0.03**
Non-Caring	-0.02	**0.98 (0.96, 1)**	**0.02**	-0.05	**0.95 (0.93, 0.98)**	**0.0001**	0.01	—	0.43

Table 4.13. Correlations Between Domains of Parent Interaction Behaviors and Child Distress Ratings by Various Raters

Parent Behavior Domain	Parent-Report			Medical Staff-Report			Observer-Report			Child-Report		
	Estimate	OR (95% CI)	p	Estimate	OR (95% CI)	p	Estimate	OR (95% CI)	p	Estimate	OR (95% CI)	p
Verbal Domains												
Knowing	0.02	—	0.38	-0.001	—	0.95	0.02	—	0.19	0.04	**1.04 (1,1.07)**	**0.045**
Being with	-0.05	—	0.31	-0.14	—	0.21	-0.13	—	0.07	0.04	—	0.41
Doing for	-0.004	—	0.5	0.01	—	0.37	0.01	—	0.2	0.001	—	0.93
Maintaining Belief	-0.003	—	0.9	0.04	—	0.17	0.05	**1.05 (1.01, 1.11)**	**0.03**	-0.01	—	0.63
Enabling	0.02	**1.02 (1.01, 1.04)**	**0.004**	0.02	**1.02 (1.01, 1.03)**	**0.001**	0.03	**1.03 (1.01, 1.05)**	**0.001**	0.01	—	0.06
Non-Caring	0.04	**1.04 (1.01, 1.08)**	**0.02**	0.03	—	0.06	0.04	—	0.14	0.03	—	0.15
Nonverbal Domains												
Being with	0.06	**1.06 (1.02, 1.09)**	**0.004**	0.03	**1.03 (1, 1.07)**	**0.048**	0.06	**1.06 (1.02, 1.12)**	**0.002**	0.05	**1.05 (1.01, 1.09)**	**0.01**
Doing for	-0.01	—	0.82	-0.0032	—	0.96	0.11	—	0.27	0.03	—	0.54
Enabling	0.05	**1.05 (1.02, 1.1)**	**0.006**	0.04	**1.04 (1.01, 1.07)**	**0.02**	0.04	**1.05 (1, 1.09)**	**0.03**	0.05	**1.05 (1, 1.1)**	**0.04**
Maintaining Belief	-0.63	—	**0.84**	0.81	—	0.84	-7.7	—	0.25	-1	—	0.7
Non-Caring	-0.03	**0.97 (0.95, 0.99)**	**0.002**	-0.03	**0.97 (0.96, 0.99)**	**0.002**	-0.02	**0.98 (0.96, 1)**	**0.02**	-0.02	—	0.07

Table 4.14. Correlations Between Domains of Parent Interaction Behaviors and Child Cooperation Ratings by Various Raters

Parent Behavior Domain	Parent-Report			Medical Staff-Report			Observer-Report		
	Estimate	OR (95% CI)	p	Estimate	OR (95% CI)	p	Estimate	OR (95% CI)	p
Verbal Domains									
Knowing	-0.02	—	0.23	-0.01	—	0.54	0.01	—	0.55
Being with	0.08	—	0.44	0.01	—	0.89	0.01	—	0.9
Doing for	-0.01	—	0.19	-0.004	—	0.52	-0.02	**0.98 (0.97, 0.99)**	**0.005**
Maintaining Belief	-0.03	—	0.33	-0.02	—	0.43	-0.07	**0.93 (0.88, 0.98)**	**0.01**
Enabling	-0.03	**0.97 (0.95, 0.98)**	**0.0001**	-0.03	**0.97 (0.95, 0.98)**	**<0.0001**	-0.03	**0.97 (0.96, 0.99)**	**0.007**
Non-Caring	-0.05	—	0.12	-0.09	**0.91 (0.86, 0.96)**	**0.0004**	-0.06	—	0.06
Nonverbal Domains									
Being with	-0.07	**0.93 (0.9, 0.96)**	**0.0002**	-0.07	**0.93 (0.9, 0.97)**	**0.001**	-0.05	**0.95 (0.91, 0.99)**	**0.02**
Doing for	-0.001	—	0.99	-0.01	—	0.87	-0.08	—	0.38
Enabling	-0.04	**0.96 (0.93, 0.99)**	**0.008**	-0.06	**0.94 (0.9, 0.97)**	**0.001**	-0.04	**0.96 (0.93, 1)**	**0.049**
Maintaining Belief	2.88	—	0.71	-5.28	—	0.25	-4.22	—	0.59
Non-Caring	0.04	**1.04 (1.02, 1.06)**	**<0.0001**	0.03	**1.03 (1.01, 1.05)**	**0.002**	0.03	**1.03 (1.01, 1.06)**	**0.004**

Table 4.15. Time-Window Sequential Analyses of Parent Interaction Behaviors and Subsequent Display of Distress by the Child

	Child Behavioral Distress (Mean Yule's Q)			Child Verbal Distress (Mean Yule's Q)		
Parent Interaction Behavior	**T_2**	**T_3**	**T_4**	**T_2**	**T_3**	**T_4**
Verbal Behaviors						
Avoiding Assumption	-0.59 (n = 15)	-0.57 (n = 16)	-0.58 (n = 9)	-0.99** (n = 11)	-0.65 (n = 11)	—
Sharing Feelings	—	—	—	—	—	—
Protecting	—	-0.99* (n = 6)	—	—	—	—
Comforting	-0.54 (n = 17)	-0.75 (n = 20)	-0.19 (n = 11)	-0.77 (n = 14)	-0.46 (n = 12)	—
Believing in/Esteem	-0.49 (n = 11)	-0.68 (n =12)	-0.52 (n = 11)	-0.99** (n = 7)	-0.99** (n = 8)	—
Informing/Explaining	-0.41 (n = 16)	-0.41 (n = 21)	-0.47 (n = 11)	-0.53 (n = 12)	-0.21 (n = 14)	0.03 (n = 6)
Validating	-0.04 (n = 13)	-0.42 (n = 16)	-0.62 (n = 9)	-0.35 (n = 10)	-0.51 (n = 11)	—
Supporting/Allowing	-0.69 (n = 6)	-0.62 (n = 10)	-0.68 (n = 6)	—	-0.72 (n = 6)	—
Criticizing	-0.73 (n = 6)	—	—	—	—	—
Apologizing	—	—	—	—	—	—
Burdens/Intrusive Questions	-0.79 (n = 7)	-0.53 (n = 7)	—	—	-0.71 (n = 7)	—
Nonverbal Behaviors						
Eye Contact	-0.99** (n = 8)	-0.72 (n = 7)	-0.99** (n = 7)	—	-0.99* (n = 7)	—
Distance Close Enough to Touch	-0.60 (n = 18)	-0.24 (n = 21)	-0.42 (n = 13)	-0.87** (n = 14)	-0.87** (n = 14)	-0.99* (n = 6)
Nonverbal Comforting	-0.99** (n = 8)	-0.79* (n = 9)	-0.99** (n = 6)	—	—	—
Nonverbal Supporting/Allowing	-0.94** (n = 16)	-0.61 (n = 17)	-0.99** (n = 11)	-0.74 (n = 11)	-0.75 (n = 11)	—
Nonverbal Believing in/Esteem	—	—	—	—	—	—
Less Availability	-0.75 (n = 17)	-0.67 (n = 16)	-0.82** (n = 11)	-0.85** (n = 13)	-0.99** (n = 12)	-0.99 (n = 6)

Note: Yule's Q represents the likelihood that the child behavior will follow the parent behavior within a 5−second window. Yule's Q ranges from −1 to 1; positive values indicate that the specific child behavior is more likely to follow the parent behavior than it is at any other time, while negative values indicate that specific child behavior is less likely to follow the parent behavior than it is at any other time. In this study, Yule's Q values did not meet the normal distribution due to the small sample size; therefore, binomial tests were conducted to determine whether the distribution of positive and negative Yule's Q values was significantly different from that expected by chance. Participants must have displayed the parent or child behavior of interest to receive a Yule's Q score; therefore, sample sizes are different for each analysis. "—" indicates sample size less than 5 in that category.
Levels of significance for binomial test were $^{*}p < 0.05$, $^{**}p < 0.01$

Table 4.16. Time-Window Sequential Analyses of Child Displays of Distress and Subsequent Display of Parent Interaction Behaviors

	Child Behavioral Distress (Mean Yule's Q)			Child Verbal Distress (Mean Yule's Q)		
Parent Interaction Behavior	**T_2**	**T_3**	**T_4**	**T_2**	**T_3**	**T_4**
Verbal Behaviors						
Avoiding Assumption	-0.39 (n = 15)	-0.50 (n = 15)	-0.78* (n = 9)	-0.99** (n = 11)	-0.52 (n = 11)	—
Sharing Feelings	—	—	—	—	—	—
Protecting	—	-0.99* (n = 7)	—	—	-0.99* (n = 6)	—
Comforting	-0.37 (n = 17)	-0.58 (n = 19)	0.00 (n = 11)	-0.78 (n = 14)	-0.47 (n = 12)	—
Believing in/Esteem	-0.55 (n = 11)	-0.56 (n = 12)	-0.40 (n = 11)	-0.99* (n = 7)	-0.78 (n = 8)	—
Informing/Explaining	-0.74 (n = 16)	-0.43 (n = 19)	-0.44 (n = 13)	-0.58 (n = 12)	-0.31 (n = 14)	0.43 (n = 6)
Validating	-0.59 (n = 13)	-0.27 (n = 16)	-0.35 (n = 9)	-0.30 (n = 10)	-0.56 (n = 12)	—
Supporting/Allowing	-0.83 (n = 6)	-0.64 (n = 10)	-0.69 (n = 6)	—	-0.68 (n = 6)	—
Criticizing	-0.67 (n = 6)	—	—	—	—	—
Apologizing	—	—	—	—	—	—
Burdens/Intrusive Questions	-0.17 (n = 7)	-0.45 (n = 6)	—	—	-0.46 (n = 7)	—
Nonverbal Behaviors						
Eye Contact	-0.35 (n = 7)	-0.45 (n = 6)	-0.99* (n = 7)	—	-0.74 (n = 7)	—
Distance Close Enough to Touch	-0.65 (n = 18)	-0.37 (n = 20)	-0.57 (n = 13)	-0.89** (n = 14)	-0.87** (n = 14)	-0.99* (n = 6)
Nonverbal Comforting	-0.99** (n = 8)	-0.79 (n = 7)	—	—	—	—
Nonverbal Supporting/Allowing	-0.83 (n = 16)	-0.67 (n = 15)	-0.99** (n = 12)	-0.79 (n = 11)	-0.33 (n = 10)	—
Nonverbal Believing in/Esteem	—	—	—	—	—	—
Less Availability	-0.72 (n = 16)	-0.90** (n = 16)	-0.99** (n = 10)	-0.89** (n = 13)	-0.99** (n = 12)	-0.99* (n = 6)

Note: Yule's Q represents the likelihood that the parent behavior will follow the child behavior within a 5−second window. Yule's Q ranges from −1 to 1; positive values indicate that the specific parent behavior is more likely to follow the child behavior than it is at any other time, while negative values indicate that specific parent behavior is less likely to follow the child behavior than it is at any other time. In this study, Yule's Q values did not meet the normal distribution; therefore, binomial tests were conducted to determine whether the distribution of positive and negative Yule's Q values was significantly different from that expected by chance. Participants must have showed the child and adult behavior of interest to receive a Yule's Q score; therefore, sample sizes are different for each analysis. "—" indicates sample size less than 5 in that category.
Levels of significance for binomial test were: $^{*}p < 0.05$, $^{**}p < 0.01$.

Study Aim 3: Temporal Relations Between Parent Interaction Behaviors and Child Verbal and Behavioral Distress

Child verbal and behavioral distress following parent interaction behaviors. Table 4.15 shows the nature and strengths of the temporal relations between parent interaction behaviors and subsequent child displays of distress. A significant proportion of children displayed less behavioral distress across study time-points following parent nonverbal interaction behaviors—eye contact (both Yule's Qs -0.99), comforting (Yule's Qs -0.79~ -0.99), supporting/allowing (Yule's Qs -0.94~ -0.99), and less availability (Yule's Q -0.82)—than at any other time. Children were also less likely to display behavioral distress following parental verbal protecting behavior than at any other time (Yule's Q -0.99).

Similarly, a significant proportion of children displayed less verbal distress following parent nonverbal interaction behaviors—eye contact (Yule's Q -0.99), distance close enough to touch (Yule's Qs -0.87~ -0.99), supporting (Yule's Qs -0.94~ -0.99), and less availability (Yule's Qs -0.85~ -0.99)—than at any other time. Children displayed less likely verbal distress following parent avoiding assumption and believing in/esteem behaviors (Yule's Qs -0.99) than at any other time. These results suggested that use of verbal behaviors (e.g., protecting and believing in/esteem) and nonverbal behaviors (e.g., eye contact and distance close enough to touch) by parents can keep children from verbal or behavioral distress. However, children's verbal and behavioral distress showed no significant change following parent non-caring behaviors such as criticizing and apologizing.

Parent interaction behaviors following child verbal and behavioral distress. Table 4.16 shows the nature and strengths of temporal relationships between parent interaction behaviors subsequent to child verbal and behavioral displays of distress. Specifically, parents displayed fewer nonverbal behaviors across time-points following child behavioral distress—eye

contact (Yule's Q -0.99), comforting (Yule's Q -0.99), supporting (Yule's Q -0.99), and less availability (Yule's Qs -0.90~ -0.99)—than at any other time. Parents also displayed fewer avoiding assumption (Yule's Q -0.78) and protecting behaviors (Yule's Q -0.99) while their children were displaying behavioral distress.

Similarly, parents displayed fewer nonverbal behaviors following child verbal distress—distance close enough to touch (Yule's Qs -0.87~ -0.99) and less availability (Yule's Qs -0.89~ -0.99)—than at any other time. When the child displayed verbal distress, the subsequent use of avoiding assumption (Yule's Q -0.99), protecting (Yule's Q -0.99), and believing in/esteem behaviors (Yule's Q -0.99) were less than at any other time. In other words, these results suggested that parent verbal behaviors (e.g., protecting and believing in/esteem) and nonverbal behaviors (e.g., eye contact and distance close enough to touch) were lower while a child was engaged in verbal and behavioral distress. No significant correlations were found with respect to parent verbal non-caring behaviors while a child was engaged in verbal and behavioral distress.

Discussion

This study investigated the change of parent interaction behaviors over the course of repeated port starts and the temporal relations between parent interaction behaviors and child distress during port starts. We found that parents displayed more nonverbal interaction behaviors over time, suggesting that parents gradually adjust themselves to use more nonverbal behaviors as their child experienced more port procedures. Additionally, parents seem to display more verbal and nonverbal caring behaviors but less nonverbal non-caring behaviors if the parent showed higher distress or if their child suggested higher child distress. The time-window sequential analyses confirmed that parent nonverbal caring behaviors seem to cue the less likelihood of child verbal and behavioral distress, suggesting that parent caring behaviors can

keep children from being distressed during painful procedures; meanwhile, parent caring behaviors seem to keep children from distress if the child is in distress. Although studies have reported the correlations between parent interaction behaviors and child distress (Chorney et al., 2013; Taylor, Sellick, & Greenwood, 2011), the temporal relations between parent and child interactions are rarely investigated over time during painful procedures such as port starts.

More parents attempted to use verbal (caring and non-caring) interaction behaviors during port starts compared with pre- and post-port starts. This pattern of parent interaction behaviors keeps consistent with the pattern of child verbal and behavioral distress. Not surprisingly, a "caring" parent should use more verbal interaction behaviors to help their child go through painful medical procedures because child pain and distress increase during the procedures (Blount et al., 1989; Cline et al., 2006). Compared with parent verbal behaviors, parent nonverbal behaviors seemed to have no change or to decrease during port starts compared with pre-port starts. Further analysis indicated that more and more parents displayed nonverbal caring behaviors during port starts over the course of repeated port starts. Possible explanations of these findings included: 1) Fear is a result of skill deficits (Bandura, 1977); therefore, parents might lack of belief to manage medical procedures that can bring fear and distress to parents at the beginning. As children receive more procedures, parents gradually became familiar with the procedures and thus use more nonverbal caring behaviors; and 2) owing to the changes of research and clinical practice in medical procedures, more educational and advising resources are available to facilitate parents helping their child go through these procedures (Czarnecki et al., 2011; Lee, Yamada, Kyololo, & Stevens, 2014). Our study will add new knowledge to current literature by providing an explicit solution to design intervention programs based on a caring perspective.

Parent caring and non-caring interaction behaviors (except less availability) showed positive correlations with parent distress and child distress but negative correlations with child cooperation during repeated port starts. Less availability showed negative correlations with parent distress and child distress but positive correlations with child cooperation. As the first study to investigate parent interaction behaviors under a theoretical foundation—Swanson's Theory of Caring, our results were different from previous studies. Previous studies have classified parent-child interaction behaviors into different groups (e.g., coping-promoting and distress-promoting behaviors), suggesting that parent distress-promoting behaviors can increase child's pain and distress whereas parent coping-promoting behaviors can reduce child's pain and distress during painful procedures (Blount et al., 2001; Chorney et al., 2013; Taylor et al., 2011). These differences can be interpreted as: First, previous studies aimed at distinguishing parent interaction behaviors that can contribute to child's negative treatment-related responses such as pain and distress (Blount et al., 2001; Chorney et al., 2013; Taylor et al., 2010). However, the current study attempted to articulate parent interaction behaviors from a theory-based perspective. All parental behaviors were grouped into caring and non-caring domains based on operational definitions and codes. Second, child distress behaviors can trigger parent caring or non-caring behaviors. In other words, the higher distress a child displays, the more caring interaction behaviors a parent will provide; similarly, the better cooperation a child shows, the less caring interaction behaviors a parent will provide. Third, parents with a higher level of distress might indicate more concerns regarding painful procedures according to their experience and child's disease conditions, leading to higher use of interaction behaviors by parents.

Further sequential analyses showed that parent interaction behaviors based on Swanson's Theory of Caring can keep children from being distressed, especially for parent nonverbal

interaction behaviors such as eye contact and distance close enough to touch. Conversely, if a child was already distressed, child was less likely to remain distressed while parents are using verbal caring behaviors (e.g., avoiding assumption and believing in/esteem) and nonverbal caring behaviors. This is the first study to explore parent caring behaviors in an observational study and understand the impact of these behaviors on child's distress during repeated painful procedures. Our findings are congruent with previous studies to support the contributions of Swanson's Theory of Caring. Swanson et al. (1999, 2009) investigated caring-based interventions among women after miscarriage and found that these interventions can reduce women's overall emotional disturbance, anger, and depression. This study expanded the use of Swanson's theory to study parent-child interactions during port starts and provided a foundation to design evidence-based interventions to reduce child's pain and distress during medical procedures.

Findings of this study have methodological and clinical applications. First, mixed modeling with GEE was used to explore the change of parent verbal and nonverbal interaction behaviors during repeated port starts. These findings can help health care providers detect the trajectory changes of targeted parent interaction behaviors, especially in children receiving continuous painful procedures such as port starts. Additionally, the majority of results in correlational analyses seem different from previous studies (Blount et al., 2001; Chorney et al., 2013). For example, the domain of enabling (e.g., informing/explaining and support/allowing) was positively correlated with child distress; however, previous studies have regarded these behaviors as coping-promoting behaviors that showed negative correlations with child distress (Blount et al., 1989). It is impossible to distinguish these different findings based on the correlational analysis because we do not know whether parent interaction behaviors are triggering more child distress and less cooperation or child verbal and behavioral distress cue

more parent interaction behaviors, or other third variables contribute to the different findings (Chorney et al., 2013). In this study, the time-window sequential analyses support how to explain the findings despite the positive correlational findings and provide more evidence that the child would be less likely to become distressed following parent caring behaviors during port starts. The sequential analyses seem to support that parent caring behaviors are similar to distress-reducing behaviors. Last, this is the first study to explore parent-child interactions with a clear theoretical basis. It suggested the use of the caring behaviors could significantly decrease child's distress, especially these nonverbal indicators. These findings provide evidence-based information for interventions to reduce child's pain and distress in future.

This study added to previous studies in several ways. Although previous literature has examined the parent-child interactions in a variety of painful medical procedures, this study addressed the parent interaction behaviors from a caring perspective. Based on Swanson's Theory of Caring, findings of this study have expanded the use of caring theory in the parent-child interaction studies and validated the application of this theory in observational studies. Parent interaction behaviors that were developed based on the theoretical foundation can be used to design intervention programs to help children go through the traumatic procedures. This study also investigated parent (caring and non-caring) nonverbal behaviors that are rarely investigated in previous studies (Blount et al., 2008; Peterson et al., 2007). Studying parent nonverbal behaviors can broaden our understanding of parent-child interaction phenomenon and provide new solutions to design interventions during medical procedures. This study also answered an important question regarding the trajectory change of parent interaction behaviors over time, suggesting that parents are displaying more nonverbal caring behaviors as children receive more painful procedures. This finding can help parents adjust their behaviors that would benefit their

child's experience during cancer treatment. Last, this study used the correlational analysis and time-window sequential analysis to examine the relations between parent interaction behaviors and child's treatment-related responses. This study addressed an important research gap—studying the parent-child interactions under a theoretical basis using the new method of time-window sequential analysis.

This study has several limitations. First, this study had a small sample size, which might restrict the use of more conservative methods and reduce the power of data analysis. In the time-window sequential analyses, temporal relations between parent interaction behaviors and child distress cannot be computed for some observational behaviors due to the small sample size. We selected the mixed modeling with GEE that has simplified the correlations between parent-child interactions in terms of the small sample size. Second, the temporal relations between parent and child interactions were reported by the sequential analysis; however, sequential analysis does not indicate a causal relationship in nature. Thus, causation cannot be inferred from our findings. Future experimental studies can be developed to examine the casual relationships by manipulating significant parent verbal and/or nonverbal behaviors. Third, this study did not examine how demographic variables (e.g., child age and length of procedure) and parent dispositional attributes (e.g., parent positive and negative affections) moderate the relationships between parent interaction behaviors and child distress. For example, parent-child interaction relationships might be different between parents with higher positive affections and those with lower positive affections. Future studies should explore the moderators to the parent-child interaction relationships during painful medical procedures. Last, this study did not assess child's resilience behaviors following parent interaction behaviors. Previous studies have reported that parent nonprocedural talk and verbal distraction were more likely to stimulate child's coping

strategies such as the use of nonprocedural talk and verbal distraction (Chorney et al., 2013). Future work should examine the impact of parent caring behaviors on child's resilience behaviors along with child distress behaviors during painful medical procedures.

Conclusion

This study explored the trajectory changes of parent interaction behaviors and the relations between parent caring and non-caring behaviors and child distress during cancer treatment−related port starts. As a child experiences more port starts over time, more parents are displaying nonverbal interaction behaviors but parent verbal behaviors remain stable. Correlational analyses in this study indicated that parent interaction behaviors based on Swanson's Theory of Caring can significantly affect parent distress, child distress, and child cooperation during port starts. Time-window sequential analyses further indicated that parent caring behaviors can significantly decrease child's display of verbal and behavioral distress and the use of caring behaviors by parents can result in less distress behaviors even if the child is in distress. All these findings suggested that future intervention programs can be designed and tested to facilitate parents to effectively use caring verbal and nonverbal behaviors. More studies need to explore the moderators and/or mediators of the relationships between parent and child interactions during medical procedures.

Taken together, findings of this study contribute to current literature in three ways—expanding the use of Swanson's Theory of Caring in an interaction phenomenon, validating the impact of theory-based parent verbal and nonverbal behaviors on a child's treatment-related responses via time-window sequential analyses, and providing a new solution to design evidence-based interventions to improve child's and parent's well-being during cancer-related painful procedures.

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CHAPTER 5. BEING A "CARING PARENT" IS THE BEST THING PARENTS CAN DO FOR THEIR CHILD DURING CANCER TREATMENT−RELATED PROCEDURES

Prologue

Children with cancer undergo various cancer therapies that are accompanied by painful and distressing medical procedures such as lumbar punctures (LPs), bone marrow aspirations (BMAs), and port starts (Blount, Piira, Cohen, & Cheng, 2006; Hockenberry et al., 2011). How to reduce the negative consequences of these procedures on children and their parents is an important issue in supportive cancer care. Parents play important roles as their child's protector and supporter (Bowlby, 1988), especially when their child is battling with cancer and experiencing repeated treatment-related painful procedures. Parents also expressed various emotional changes (Power, Liossi, & Franck, 2007; Felicity et al., 2012) that might affect the nature of parental behaviors to support and protect their child during cancer treatment−related procedures.

According to previous study, supportive parents attempt to keep the child under their wings during medical procedures (Karlsson, Englund, Enskär, & Rydström, 2014). Thus, parents can support and protect their child in a variety of ways, including allowing the child to express their feelings, helping the child understand the procedures, attempting to provide a rewarding and relaxing context, and seeking additional support from health care providers and other family members (Blount et al., 2001; Cline et al., 2006; Karlsson et al., 2014). Appropriate use of these supportive behaviors can heighten more positive treatment-related responses (e.g., child cooperation and parent satisfaction with the provision of health care) and fewer negative

treatment-related responses (e.g., child pain and child distress). Some parents also display unsupportive behaviors during cancer treatment−related procedures. These behaviors have been named "distress-promoting behaviors", including apologizing, criticizing, distancing, and invalidating (Blount et al., 1989; Cline et al., 2006). These behaviors can heighten a child's negative treatment−related responses, leading to more pain and distress but less cooperation (Cline et al., 2006; Spagrud et al., 2008). Studies on parent-child interactions during cancer treatment−related procedures can not only distinguish parent verbal and nonverbal behaviors that contribute to improving a child's experience from those that exacerbate child's suffering but also provide a foundation to design intervention programs to facilitate children and their parents to cope with these continuous procedures during cancer treatment.

This dissertation research asked about what interaction behaviors are parents presenting and how these behaviors influence child's treatment-related responses during continuous port starts from a caring perspective. Specific aims of this dissertation were threefold: First, to review the extant observational parent-child interaction coding systems during painful procedures; second, to develop a reliable and valid coding system to capture parent interaction behaviors during cancer treatment−related procedures based on Swanson's Theory of Caring; and third, to examine the relationships between parent interaction behaviors and child distress using both the correlational analysis and the time-window sequential analysis. Findings of this dissertation help us understand what a "caring" parent can do for their child during painful cancer procedures.

Synthesis of Findings and Implications: What Have We Learned?

What we have learned in this dissertation research is discussed in the following three areas: 1) observational measures of parent-child interactions, 2) relationships between parent

interaction behaviors and child treatment-related responses, and 3) methodological insight for an observational study.

Observational Measures of Parent-Child Interactions

Theoretical foundation. As a start of our journey toward this dissertation, a systematic review of 15 observational coding systems of parent-child interactions during painful procedures was conducted (Chapter 2). The strengths of the extant coding systems include: a) assessing parent-child interaction behaviors across different age groups and in various procedure-related painful contexts; b) focusing on both parent and child interaction behaviors (10/15, 66.7%), and c) showing acceptable evidence of reliability and validity. Nevertheless, these observational coding systems have limitations that have been addressed in previous studies (Blount et al., 2008; Cline et al., 2006) and this dissertation: a) the majority of observational coding systems were not built based on clear theoretical foundation; b) parent nonverbal behaviors were under-represented in older children (ages 3–18 years); and c) only a small portion of the existing coding systems (4/15, 26.7%) was evaluated as well-established assessments by the criteria of the Society of Pediatric Psychology Assessment Task Force (SPP-ATF).

To address the limitations of extant observational coding systems, the Parent Caring Response Scoring System (P-CaReSS) was developed using the hybrid approach of inductive and deductive coding and its preliminary reliability and validity was tested as well (Chapter 3). Observational codes in the P-CaReSS were built based on a middle-range theory—Swanson's Theory of Caring. According to Swanson's work (1991, 2013), explicit definitions and operational constructs of the five caring domains have been reported. The empirical evidence (Swanson, 1999; Swanson, Chen, Graham, Wojnar, & Petras, 2009) has supported relationships among the caring domains in Swanson's theory. The newly developed P-CaReSS not only well

represented the five caring domains in the Theory of Caring but also attempted to capture non-caring behaviors during painful medical procedures. Further testing of the P-CaReSS supported its IRR with percent agreements > 0.08 for each domain and its validity for use in children during cancer treatment−related port starts.

This dissertation supported that it is feasible to develop an observational tool based on a middle-range theory. Swanson's Theory of Caring has been tested in women suffering from miscarriage and parents of infants with severe illness (Swanson, 1990, 1999; Swanson et al., 2009). This is the first study to examine parent interaction behaviors during painful medical procedures with the support of this theory. This dissertation supported that Swanson's theory can be extended to study parent-child interactions in an observation study. Compared with previous measures (e.g., the CAMPIS-R [Blount et al., 1997]), the newly developed P-CaReSS has the following strengths: a) focusing on parent-centered behaviors such as caring behaviors without specific assumptions regarding the impact of these behaviors on child's behaviors, and b) being developed on the basis of a clear theoretical foundation. Thus, this dissertation research could contribute to the measurement of parent-child interactions in two ways—providing evidence for other researchers and clinicians to select appropriate measures when studying parent-child interactions and validating a new tool to assess parent interaction behaviors under a theoretical foundation.

Verbal and nonverbal behaviors as a whole. Parent-child interaction is a complex phenomenon that cannot be captured in a single dimension. Blount and colleagues (2008) suggested the necessity to explore this phenomenon via a variety of dimensions such as verbal, nonverbal, and emotional domains. Until now, no study has distinguished the contribution of parent verbal, nonverbal, and emotional behaviors from each other during painful medical

procedures because all these dimensions are intricately connected with each other. Importantly, the majority of extant observational coding systems concentrated on parent verbal behaviors only, leaving parent nonverbal and emotional behaviors less explored during painful procedures. Therefore, observational codes in the P-CaReSS fill the gap by adding assessment of parent nonverbal and emotional behaviors during painful medical procedures.

Relations Between Parent Interaction Behaviors and Child Treatment-Related Responses

A caring parent. Parents play critical roles in caring for their child during medical procedures during the trajectories of cancer diagnosis and cancer treatment. Recently the paradigm shifted to studying how parents interact with their child during painful procedures rather than whether the parent is present; parent interactions and parent presence can both affect children's treatment-related experiences (Chorney, Tan, & Kain, 2013; Cline et al., 2006; Spagrud et al., 2008). In this dissertation, we investigated change in parent interaction behaviors over the repeated port starts. The temporal relations between parent interaction behaviors and child verbal and behavioral distress were further examined using the newly developed P-CaReSS. The results showed that parents display more nonverbal caring behaviors as the child undergoes additional port starts. The results of the time-window sequential analysis suggest that parent caring behaviors can significantly reduce child distress, and also parent caring behaviors can reduce child distress even if the child is engaged with distress. The conclusion is that "caring" parent can adjust their behaviors over time to help their child cope with painful procedures.

When looking at parent interaction behaviors in detail, the results suggest that "caring" parents are not only doing what they can to help the child or control the child's behaviors but also encouraging the child to express feelings and tell parents what he or she needs (Karlsson et al., 2014). For instance, parents can use "Doing for" and "Enabling" behaviors to support their

child throughout painful procedures and also initiate "Knowing" and "Maintaining Belief" behaviors to know their child before proceeding with any interventions. Thus, the results in this dissertation provide further support for the caring constructs of Swanson's theory and illuminate what a "caring" parent can do for their children during procedures such as keeping children under their protection to guarantee their sense of security and comfort during painful procedures, letting children speak for themselves and respecting children's choices about the strategies they prefer to use to cope with painful medical procedures. Although much research has been conducted to examine the parent-child interaction phenomenon, there is still a gap regarding the meaning of "caring parent" from parents and children's perspectives. Future research can be designed to understand what verbal, nonverbal or emotional indicators "caring parents" can utilize during medical procedures from the perspectives of children and parents.

Caring versus non-caring behaviors. Parent verbal (e.g., protecting) and nonverbal caring behaviors (e.g., eye contact) can reduce the likelihood that a child will verbalize distress or become nonverbally distressed whether a child is engaged with distress or not. These findings supported our hypotheses and the caring constructs of Swanson's theory (Swanson, 1991), indicating that parent caring behaviors can help children cope with painful procedures. These caring behaviors seem to play similar roles to coping-promoting behaviors as reported in previous studies (Blount et al., 1989, 2001). In this study, parent verbal non-caring behaviors (e.g., criticizing) have no significant effect on child distress. This finding did not support previous studies which suggested that non-caring behaviors can increase child's negative response during painful procedures (Chorney, Tan, & Kain, 2013; Cline et al., 2006; Spagrud et al., 2008). The conclusion cannot be made for these non-caring behaviors due to the small sample size and the lower percentage of occurrence of these behaviors in this dissertation. Future

studies should test these non-caring behaviors in a large sample size of children with other cancer treatment−related procedures.

Verbal versus nonverbal behaviors. This dissertation research contributes to current literature by addressing specific parent nonverbal behaviors during painful procedures. Findings indicated that more parents are using nonverbal behaviors over the repeated port start procedures. Importantly, these nonverbal behaviors can help the children cope with procedure-related distress. As one of few studies examining parent nonverbal interaction behaviors, Peterson and colleagues (2007) have reported the relationships between parent personal distances and touch on child's pain and distress during cancer treatment−related procedures. In a new study, Schinkel and colleagues (2016) further addressed the lack of evidence on parent nonverbal behaviors and compared mother's and father's nonverbal behaviors during child pain. However, this study studied parent nonverbal behaviors in an experimental cold pressor task in a laboratory. This dissertation research provided clear evidence about parent nonverbal behaviors that can serve as the basis for design interventions to maximize effective coping and emotional well-being for a child and their parents during cancer treatment−related procedures.

Conceptual framework. In this dissertation, both correlational analysis and time-window sequential analysis were performed to examine the relations between parent interaction behaviors and child responses during cancer-related port starts. Bidirectional effects were found between parent and child during interactions as reported in previous studies (Caldwell-Andrews, Blount, Mayes, & Kain, 2005). These results can help identify the behavioral precedents of negative child behaviors (e.g., pain and distress) and advance our understanding of when and how targeted interventions can be implemented for children and their parents during painful procedures. Besides the relationships of behavioral interactions between parent and child, a

group of factors can influence these relationships. Calldwell et al. (2005) and McCarthy et al. (2010) have articulated these factors in several categories, including parent characteristics, child characteristics, procedure characteristics, and parent behavioral responses. Penner and colleagues (2008) found that parent dispositional status such as empathic concerns and empathic distress can also influence children's treatment responses. Therefore, the moderating/mediating variables that might affect the response of a child to any particular parent behavior have to be considered in the model when studying parent-child interactions during painful procedures from a caring perspective (Figure 5.1).

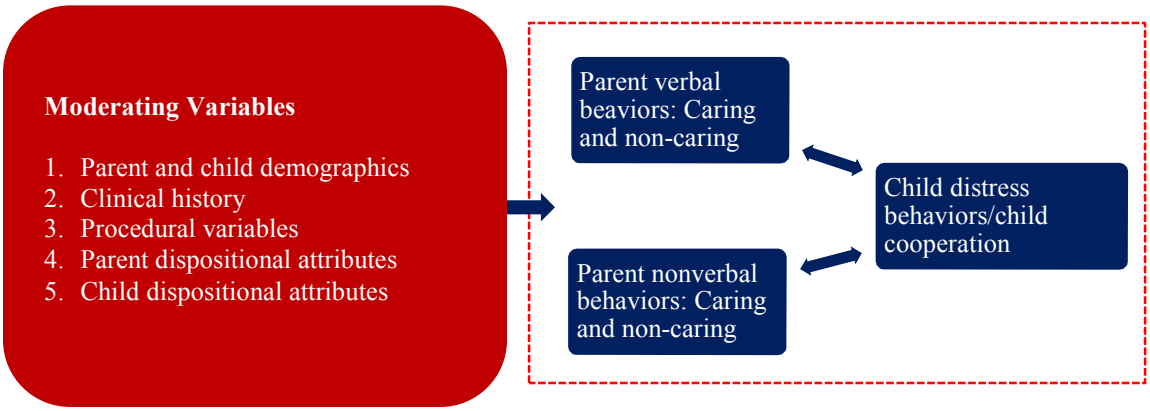

Figure 5.1. Conceptual framework.

Methodological Insight for an Observational Study

The observational coding systems are valuable tools to help researchers and clinicians understand complex clinical phenomena such as parent-child interactions. Studies have reported practical guidelines for developing and modifying behavioral coding systems for studies that use observational methods (Chorney, McMurtry, Chambers, & Bakeman, 2015; Sharpe, &

Koperwas, 2003). Nevertheless, a variety of factors must be considered to assure rigor and reproducibility in research that uses observational methods. According to our experience of developing, testing, and using the P-CaReSS in this dissertation research, these factors can include three aspects derived from Donabedian's model of structure, process, and outcome (SPO) (Donabedian, 1988, 2005). The SPO model was originally developed to evaluate health care services and quality of health care in three categories: structure, process, and outcome. Structure refers to the context where health care is delivered; process means the transactions between patients and healthcare providers during the delivery of health care; and outcome refers to the result of health care for patients and their family members.

Based on the SPO model, three specific aspects are addressed in developing and testing an observational coding system (Figure 5.2). The structure component for the development and testing of an observational coding system should include a friendly coding environment, adequate coding supplies and resources (e.g., coding software and funding), a multidisciplinary team with special expertise in designing and testing of observational tools and trainable coders. The process component, as the core to develop and test an observational tool, primarily should include developing the coding system using inductive and/or deductive methods, refining the coding system, pilot testing the coding system, and implementing the coding system in a representative sample. Lastly, the outcome component should include the psychometric properties of the coding system, final data coding and results, and resources use—time and cost of the coding process. Both the structure and process components can affect the outcome component. These three components in the SPO model can guide the development and testing of observational coding systems in a rigorous and scientific way.

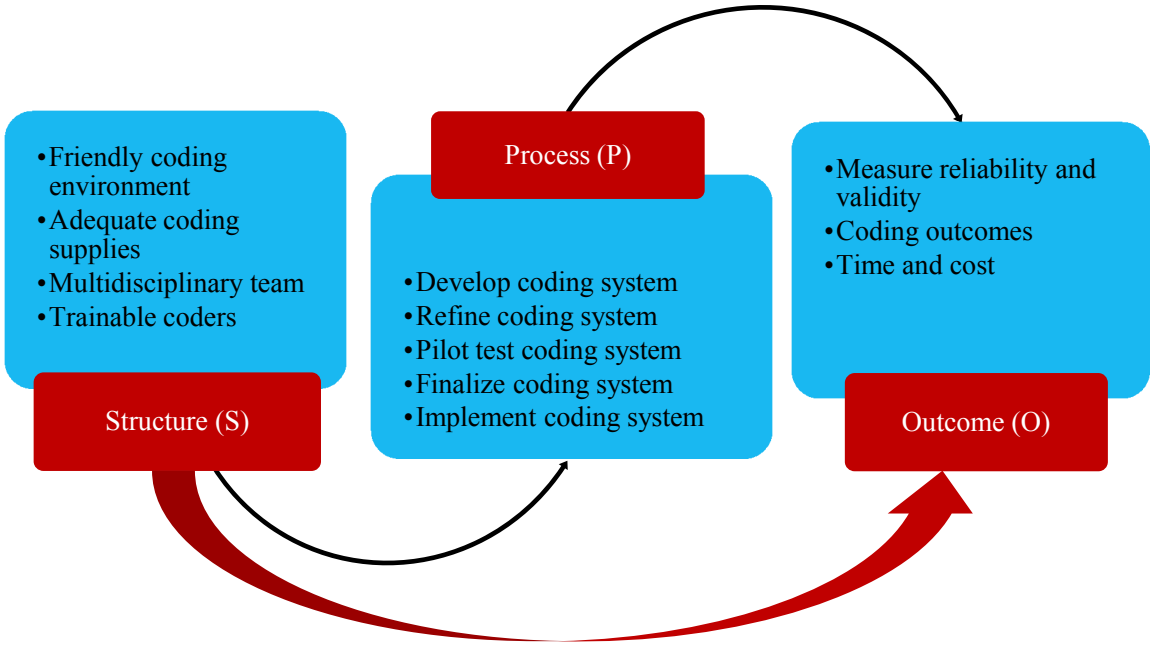

Figure 5.2. Structure, process, and outcome (SPO) framework.

Strengths of Dissertation

This dissertation investigated parent-child interactions during cancer treatment–related port starts from a caring perspective. To explicitly address current gaps in the observational tools of parent-child interactions, the new P-CaReSS was developed to assess parent verbal, nonverbal, and emotional indicators based on Swanson's Theory of Caring. The strengths of this tool include not only addressing parent interaction behaviors with a clear theoretical foundation but also expanding the use of caring theory in the observational study. Also, the P-CaReSS was developed to describe parent interaction behaviors by the timed-event coding method, which is more valid than other coding methods (e.g., interval and event coding) and provides a unique opportunity for the analysis of sequential relations between study variables (Bakeman & Quera, 2011; Chorney, Garcia, Berlin, Bakeman, & Kain, 2010). This dissertation developed a novel

tool for clinicians and researchers to use in helping children and their parents cope with painful medical procedures. The process of developing and testing the P-CaReSS provides an important exemplar of building an observational tool based on an explicit theory for future researchers.

In addition, this dissertation answered an important question regarding the trajectory change of parent interaction behaviors over time and its influence on a child's treatment responses (e.g., child distress and cooperation). The findings provide evidence of how and when to help parents adjust their verbal and nonverbal interaction behaviors to benefit a child's experience during cancer treatment−related procedures. This dissertation also provided further supported for theoretically and empirically derived constructs and linkages between them that can be used to understand the bidirectional relationships of parent-child interactions and potential moderating/mediating variables for these relationships (Caldwell-Andrews et al., 2005; McCarthy & Kleiber, 2006).

Last, a methodological strength of this dissertation lies in the use of mixed modeling with GEE and time-window sequential analysis. The former was used to explore the correlations between parent interaction behaviors and children's treatment-related responses. This method does not support inferences of causal relationships between variables. We cannot know whether parent interaction behaviors are cueing or responding to children's distress. Rather, the time-window sequential analyses were conducted to examine the temporal relations between parent interaction behaviors and children's distress and thereafter determine behavioral precedents during parent-child interactions. Taken all together, this dissertation research has strengths with respect to its theoretical foundation and methodological rigors.

Limitations of Dissertation

Several limitations have to be addressed in this dissertation. First, when systematically reviewing and evaluating observational tools of parent-child interactions, we focused on studies that reported the development and psychometric evaluation or use of specific types of coding systems. Further evaluation of how these identified coding systems were used and their performance in the intervention studies will provide more evidence to support their reliability and validity. Second, this dissertation research used a prospective design with repeated measures and mixed methods. A small sample of parents and children with homogenous demographic characteristics who experienced repeated port starts in the context of childhood cancer provided the data. Using a small sample size not only restricted the generalizability of P-CaReSS for use beyond children receiving port starts but also dictated the use of conservative methods of data analyses. For example, some Yule's Q scores for parent behaviors-child distress cannot be computed in sequential analyses due to the small sample size. Third, the thin-slice method was used in this dissertation. Although this approach showed great potential for use in the interactions between individuals (Chorney et al., 2013; Henry & Eggly, 2013), there are no guidelines for how to choose the slices of parent-child behavioral interactions during painful medical procedures. That is, the results could be different if other thin-slices had been selected from the pre-, during and post-port start phases. Lastly, time-window sequential analysis was used to examine the temporal relations between parent interaction behaviors and child verbal and behavioral distress. Sequential analysis does not support inferences of causality; thus, causation cannot be inferred from the findings. Future experimental studies could manipulate parent verbal and/or nonverbal interaction behaviors to examine the effects on children's treatment related responses.

Future Research Perspectives

This dissertation research used an original dataset (R01CA138981; PI: L. Penner) from Wayne State University/Karmanos Cancer Institute (KCI), Detroit, MI. This dissertation reported the development and preliminary testing of an observational coding system (i.e., P-CaReSS) and examined the influence of parent interaction behaviors on children's treatment-related responses (i.e., child distress and child cooperation) from a caring perspective. This dissertation has inspired future studies in the following areas:

1. Observational coding systems can be used as important resources to evaluate intervention programs on parent-child interactions. Future studies should continue evaluating the use of these measures such as the CAMPIS-R and CAMPIS-SF in the intervention studies.
2. As a newly developed tool, the psychometric properties of the P-CaReSS should be continuously examined in a larger sample of children with other cancer treatment−related painful procedures such as LPs and BMAs. Future studies should test its concurrent and predictive validity in terms of other widely used tools such as the CAMPIS-R (Blount et al., 1997) and Parent Communication Typology (Cline et al., 2006).
3. Previous studies rarely examined how the moderating and mediating variables can affect the temporal relations between parent interaction behaviors and child verbal and behavioral distress. This dissertation research did not examine the moderating factors that can influence child treatment-related responses. These variables include parent and child personal information (e.g., child age and study institution), procedural variables (e.g., length of total procedure and pre-procedure), and parent

dispositional attributes (e.g., parent positive and negative affections). Future studies should explore the moderators/mediators of parent and child interaction relationships during painful medical procedures.

4. In the sequential analysis, this dissertation research only focused on children's distress behaviors rather than their resilience behaviors. Studies have found that some parent verbal and nonverbal behaviors were more likely to stimulate a child's coping behaviors such as nonprocedural talk and verbal distraction (Chorney et al., 2013). More work needs to be done to examine the impact of parent caring behaviors on children's distress and coping behaviors during medical procedures.
5. The temporal relations in this dissertation supported that parent caring behaviors can decrease a child's verbal and behavioral distress during port starts and that caring theory can be extended to help children cope with painful medical procedures. Future experimental studies can be designed to examine parent verbal and/or nonverbal interaction behaviors on child's treatment-related responses (i.e., pain and distress) during painful medical procedures.

Epilogue

Parents act in an important role to protect and support their child during cancer treatment−related procedures. Appropriate parent interaction behaviors can significantly decrease children's level of distress and promote the level of cooperation. This dissertation research pointed out specific means to improve children's coping strategies from a caring perspective. Swanson (1991) has defined caring as "a nurturing way of relating to a valued other toward whom one feels a personal sense of commitment and responsibility." We agreed with Swanson and have seen that caring behaviors can provide a more comfortable and relaxing

treatment context during a child's port starts. By addressing an important research gap—studying parent-child interactions under a theoretical foundation by the time-window sequential analysis—we believe that parent interaction behaviors based on the caring theory can make children feel more understood, valued, safe and comforted, capable, and hopeful toward the cancer treatment−related procedures, thereby increasing emotional well-being and quality of life for both children and their parents.

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APPENDIX 1. DEFINITION AND OPERATIONALIZATION OF THE PSYCHOMETRIC PROPERTIES (BAI & JIANG, 2015)

Psychometric Property		Definition	Operationalization
Reliability	Internal consistency	Representing the average correlation of scores from a measure with the scores of all of the items in the measure (Streiner & Norman, 2008).	Cronbach's α is a commonly used indicator for this reliability. The level of acceptable Cronbach's α ranges from 0.70 to 0.90 (Streiner & Norman, 2008).
	Inter-rater (or -observer) reliability	Assessing the consistency in two or more raters/observers on their simultaneous observation and measurement (Polit & Beck, 2004; Streiner & Norman, 2008).	Cohen's kappa coefficient and intra-class coefficient (ICC) are often used indicators for this category. Acceptable level of Kappa coefficient and ICC should be > 0.60 and > 0.75, respectively (Fleiss, 1971; Streiner, 1993; Streiner & Norman, 2008).
	Intra-rater (or -observer) reliability	Assessing the consistency for one rater/observer on the observations at different occasions (Polit & Beck, 2004; Streiner & Norman, 2008).	
	Test-retest reliability	Representing the reproducible results of an assessment tool made by the same raters across at least two different occasions (Streiner & Norman, 2008).	Pearson or Spearman correlation coefficient, or paired t-test are commonly used. Acceptable level of r should be > 0.70 or p-value for t-test should be significant (Streiner, 1993; Streiner & Norman, 2008).
Validity	Content validity	Using a panel of experts to determine if the items in the tool represent appropriate and adequate content and information as well as the whole instrument (Polit & Beck, 2004; Polit, Beck, & Owen, 2007).	Content validity index (CVI) is often used and depends on the numbers of experts used. Acceptable level of CVI should be ≥ 0.9 for the total scale and > 0.78 for the items in the scale (Polit, Beck, & Owen, 2007).
	Criterion validity	Representing the association between a tool and a criterion when administered at the same time (concurrent) or at a later time (predictive) (Streiner &	Correlation coefficient is often used. Acceptable level of r should be at least 0.3-0.5 (Streiner & Norman, 2008).

		Norman, 2008).	
	Construct validity	Assessing "extent to which a tool measures what it claims or purports, to be measuring", including convergent and discriminant validity (Streiner & Norman, 2008).	
	a. Convergent validity	Assessing the ability of a tool to correlate with other measures of related construct or variables.	Correlation coefficient is used. Acceptable level of r should be at least 0.3-0.5 (Streiner & Norman, 2008).
	b. Discriminant validity	Measuring the ability of a tool to correlate with another tool measuring unrelated construct or variables.	Correlation coefficient is used. Acceptable level of r should be < 0.30 (Streiner & Norman, 2008).
Feasibility	Extent to which an assessment tool can be easily scored and interpreted (Stevens & Gibbins, 2002).		

Note: CVI = content validity index; ICC = intra-class coefficient; Permission to use this table was obtained from the editorial office of Pain Management Nursing, 2015

APPENDIX 2. CODING SYSTEM EVALUATION BASED ON THE SOCIETY OF PEDIATRIC PSYCHOLOGY ASSESSMENT TASK FORCE (SPP-ATF) CRITERIA

Coding System	I 1 = 2 different peer-reviewed authors; 2=2 same peer-reviewed authors; 3=one peer reviewed article	II 1=Available manual; 2=Unavailable manual	III 1=Good reliability and validity; 2=Moderate/vague reliability and validity	Total Evaluation
OSBD	1	1	1	W
DPIS	1	1	1	W
BAADS	1	1	2	A
CAMPIS	1	1	1	W
BAADS	1	1	2	A
CAMPIS-R	1	1	1	W
CAMPIS-SF	2	1	1	A
MAISD	1	1	2	A
P-CAMPIS	2	1	1	A
Modified CAMPIS	2	1	2	A
Parent Communication Typology	3	1	1	P
Interpersonal Distance and Touch Coding	3	1	2	P
CAMPIS-IV	3	1	1	P
PACBIS	1	1	2	A
CBCS-P	2	1	2	A
GRIDS	3	1	1	P

Note: BAADS = Behavioral Approach-Avoidance and Distress Scale; CAMPIS = Child-Adult Medical Procedure Interaction Scale; CAMPIS-IV = CAMPIS-Infant version; CAMPIS-SF = CAMPIS-Short Form; CAMPIS-R = CAMPIS-Revised; CBCS-P = Child Behavior Coding System-Post Anesthesia Care Unit; DPIS = Dyadic Prestressor Interaction Scale; GRIDS = Generation R Infant Distress Scale; MAISD = Measure of Adult and Infant Soothing and Distress; OSBD = Observational Scale of Behavioral Distress; PACBIS = Perioperative Adult Child Behavioral Interaction Scale; P-CAMPIS = Perioperative Child-Adult Medical Procedure Interaction Scale
W= well-established; A= approaching well-established; P= promising

APPENDIX 3. PARENT CARING RESPONSE SCORING SYSTEM (P-CaReSS)

Domain	Subdomain	Specific code example	Item #
Verbal (11 items)			
Knowing Striving to understand an event as it has meaning in the life of the child	**Avoiding assumptions/seeking cues:** Respect the child's decision, idea, and request; let the child participate in the procedure; understand the child's thoughts or perceptions about the procedure	• Ask child's opinion about the procedure; • Let child make decision: choose what the child likes/wants; • Let the child push the button; • You want to push the button or you want me to do it? • Are you ready? • Can you put your arms up for me? Could you just put your arms here? • Can I see your belly button? • Can you get your mouth open? • Are you hurting today? • Is this going to poke? • You smell that alcohol? • Are you sleepy? You are so sleepy today, aren't you? • Do you feel better? are you okay, baby?	**1**
Being with Being emotionally present to the child	**Sharing feelings:** share joyfulness, happiness, excitement, or celebrations with the child	• I am happy for you; • I am so proud for you; • I felt great today; • We have to celebrate we did it; • I love ya!	**2**
Doing for Doing for the child as he/she would do for oneself	**Protecting:** help child control the painful procedure or give control to the child	• You let me know, ok; • Mum will hold your hand; • I am here for you; • Mum is here for you;	**3**
	Comforting: entertain and distract strategies (Parent-To-Control)	• Humor; • Telling stories; • Do not think about it/look at me; • Talking things unrelated to the procedure, (i.e., food, toys, pets, other family members et al.); • Rewarding the child by promises; • Ask the child to sleep/nap; • Other comforting verbals, such as "Please calm down";	**4**

Enabling Facilitating the child's passage through life transitions and unfamiliar events	**Informing/explaining:** Give information and explain the procedure related to health history, disease, procedure	• They will flush your port quickly; • Let us get the woody out of your body; • It is the same thing you did before; • You should let the tube put there; • Pull the tube tightly; • She will put the tape on your body; • Now, it gonna be just a little bee sting	**5**
	Validating: Reassure the child's experience of the procedure and the progress of procedure	• It is ok; • It is almost over; • All done; that is it; it is almost the way out/almost; • I know it is hard; • I know you need help; • I know it hurts; • I know but you have to do it;	**6**
	Supporting/Allowing: guide the child to use coping strategies (Child-To-Control)	• Let us count 1, 2, 3; • Relaxation; • Take a deep breath; • Hold my hands/Pinch me when you feel the needle; • Imagine you are a Spiderman and have the strength;	**7**
Maintaining belief Sustaining faith in the child's capacity to get through an event or transition	**Believing in/holding in esteem:** praise/acknowledge the child; show encouragement to the child	• You are a hero; • Great job; • You are doing great; • You are a brave boy; • You are a sweet heart/good boy; • You have such a beautiful body;	**8**
Non-Caring Showing less parental physical and emotional presence/engagement to the child; leading increasing burdens to the child;	**Burdening by emotions/intrusive questions:** express affective distress (e.g., distress, discomfort, disgust, restless, fear and avoidance)	• I am so anxious/worried/terrified; • I hate this procedure a lot; • Argue with the child; • Are you scared/worried/anxious? • Why do you cry? • Why are you doing that? • What are you crying for?	**9**
	Apologizing: show sorrow and responsibility for the painful procedure	• I am sorry, babe; • I am sorry it will take so long; • I wish I did not hurt you at all; • I will not do this again for you;	**10**
	Criticizing: imply the child's fault or wrong-doings during the	• It is your fault; • You are just a little bitch; • Shut up;	**11**

	procedure	• That was not funny at all; • You are making me crazy; • You are a pain;	
Other	**Non-procedure related talk/questions**	• Routine talk/greetings; • School stuff not for distraction; • Conservations unrelated to the procedure agenda; • The whole day plan in the hospital or at home;	
Nonverbal (6 items)			
Being with	**Being there:** show their emotional presence by eye contact and closeness to them;	• Eye contact: a solid >2 seconds eye-to eye contact (Gaze); • Distance close enough to touch the child;	**1** **2**
Doing for	**Comforting:** entertain and distract strategies (Parent-To-Control)	• Playing with the child; • Using stuff animals or toys; • Playing with video games/cards;	**3**
Enabling	**Supporting/allowing:** providing comforting body behaviors	• Preparing the child; give the mask; put up or take off clothes; help with the procedure toward the child; check and clean the port site; lift his arms; give water; • Touch; hugging; kissing; cuddling; holding child hand; wiping child's tears; patting butt; • Positioning; repositioning; sitting on the laps; •	**4**
Maintaining belief	**Believing in/holding in esteem**	• Hand claps; • High five;	**5**
Non-Caring	**Conveying less availability**	• Distance too far to touch; • Playing with their phone; • Ignoring the child's talk; • Let the child alone;	**6**
Emotional (1 item with three levels)			
Caring		• Warm, friendly, loving, tender; • Happy, laughing, joking, joyful;	**1**
Neutral		• Matter of fact, neutral;	**2**
Non-Caring		• Anxious, nervous, scared, fear; • Frustrated, depressed, exhausted, lost, sad; • Angry, hostile, annoyed, irritated;	**3**

APPENDIX 4. THE CODING MANUAL OF THE P-CaReSS

Part I: Verbal Part II: Nonverbal Part III: Emotional

Step 1: Identify dataset

- Create a folder "P-CARE" for this study (N = 43)
- Inclusion criteria:
  - Parent-child interaction during port starts
  - Multiple port starts (≥ 2) for each child (N=43)
  - Each child with at least 3 min pre, during and post port starts (N=43)
  - All the complete video data without technical problems
  - Related dataset on other self-report and observational variables

Step 2: Familiarize with the C-PaReSS structure and definition

1) Each video will be coded for the following behavioral dimensions (see the Coding Sheet). Each of the behaviors will be coded independently.

- Verbal: Refers to parent utterances toward their child during the port start episode.
- Nonverbal: Refers to parent non-linguistic relevant behaviors, i.e., gestures, facial expressions, body posture, stance, and proximity to the child, eye movements and contact during the port start episode.
- Emotional: Refers to parent positive/negative experiences associated with particular port start episode.

2) Each dimension will be coded for the following domains if possible. Each of these behaviors will be coded independently.

- Knowing: Refers to "striving to understand an event as it has meaning in the life of the other".
- Being with: Refers to "being emotionally present to the other".
- Doing for: Refers to "doing for the other as he/she would do for oneself".
- Enabling: Refers to "facilitating the other's passage through life transitions and unfamiliar events".
- Maintaining belief: Refers to "sustaining faith in the other's capacity to get through an event or transition and face a future with meaning".
- Non-Caring: Refers to any parental verbal, nonverbal or emotional behaviors that show less parental physical and/or emotional presence to the child, or increasingly burdens to child .
- Irrelevant: Refers to parental verbal, nonverbal or emotional behaviors that are not relevant to the procedures child experiences.

Note: These first five domains are defined based on the Caring Processes. Swanson (Swanson, 1991)defines Caring as "a nurturing way of relating to a valued other toward whom one feels a personal sense of commitment and responsibility."

Step 3: Coding process

1. Upload the assigned video file for coding in the StudioCode Software.
2. All the video recordings will be categorized into three phases of treatment episode: pre-, during, and post-procedure (see **Note 1**). A 3-min or 5-min slice will be selected for each phase. Each selected slice of the treatment episode will be coded for Verbal, Nonverbal and Emotional behaviors in three passes (see **Note 2**).

   Note 1: Pre-procedure phase begins with the start of recording, and continues until immediate preparation for the procedure begins (e.g., nurse pulls up child's shirt). The procedure phase begins with immediate preparation for the procedure and concludes when the procedure is completed (e.g., child's shirt is pulled down after port start). Post-procedure continues until the end of the recording, often including a lengthy recovery time for lumbar punctures. (Cline et al., 2006)

   Note 2: For the pre- and post-procedure phases, a 5-min slice will be selected just before and after the procedure; during the procedure, a 3 min (or 5 min) coding slice will be selected by identifying the first verbal or nonverbal distress behavior related to port start; the coding slice will be the segment of video beginning at 1 min (or 2 min) before the onset of distress behavior and ending at 2 min (or 3 min) after the onset of distress behavior. (Cline et al., 2006)
3. Two trained coders will code the video-recordings using time-event sequential data coding strategy. *For all parental verbal behaviors, the **onset** of the behaviors is coded as "YES"; other periods of times without these behaviors are coded as "NO". For the nonverbal parent behaviors, the **onset** and **offset** of the behaviors (i.e., duration of the behaviors) should be coded. Parent emotional behaviors will be coded in a global at the end of each phase as "Caring, Non-Caring, or Neutral". For child behaviors, the **onset** of verbal distress, and **onset** and **offset** of behavior distress will be coded as "YES", and non-distress behaviors are coded as "NO".*
4. Fill out the Video ID, date of coding, and coder initials before each video coding.
5. Code every identifiable parent and child behaviors by the timed-event sampling method. Behaviors are mutually exclusive. The goal is to see what child behaviors (parent behaviors) are following or preceding parent caring behaviors (child behaviors) during any given 5 seconds.
6. Behaviors are coded "YES (1) or NO (0)" next to the relevant parental behavior during the appropriate time grid.
7. Ten videos will be randomly selected and coded by both trained coders to test the psychometric properties of the P-CaReSS.
8. Then, two trained coders will independently code the left videos (n = 104). We expect that each coder will code approximately 52 videos (n=43 [25 dyads with 2 repeated port starts; 18 dyads with 3 repeated port starts]).

Step 4: Finishing coding process

1. After finishing coding each video file, each complete coding will be saved as a ***Timeline*** and an ***XML***s files in Bing's Folder.
2. Once completing coding the entire dataset of videos, export the coding results for further review and data analysis.

3. First Author (J. Bai) will review the coding results and mark any inter-coder discrepancies.
4. All discrepancies will be discussed within the coding group.
5. Then coding sheets finally will be exported into SDIS file format for data analysis.

Part I: Verbal

Caring: defined as "a nurturing way of relating to a valued other toward whom one feels a personal sense of commitment and responsibility." It includes five Caring Processes: knowing, being with, doing for, enabling and maintaining belief.

- Code all parent verbalizations toward the child during port starts into the following categories:

  - Caring verbalizations: Reflects parent verbalizations that attempt to make their child feel understood (Knowing indicators), valued (Being with indicators), safe and comforted (Doing for indicators, capable (Enabling indicators), and hopeful (Maintaining Belief indicators). All these parent caring responses are assumed to relieve child's distress and pain.
    - Knowing: avoiding assumptions/seeking cues;
    - Being with: sharing feelings
    - Doing for: protecting; comforting;
    - Enabling: informing and explaining; validating; supporting/allowing
    - Maintaining Belief: believing in/holding in esteem

  - Non-caring verbalizations: Reflects parent verbalizations that will make their child feel unsafe and discomforted, incapable, and less hopeful to cope with the procedure. Parental non-caring responses are assumed to increase child's distress and pain.
    - Burdening by emotions/intrusive questions;
    - Apologizing;
    - Criticizing;

  - Neutral verbalizations: Undefined parent verbalizations that are neutral in the procedure, i.e., irrelevant talking/questions (routine talking and greetings).

  - Detail behaviors for each verbal category are listed in the following table:

Parental Verbal Behaviors

Domain	Subdomain	Specific Code Example	Item #
Verbal (11 items) **Knowing** Striving to understand an event as it has meaning in	**Avoiding assumptions/seeking cues:** Respect the child's decision, idea,	• Ask child's opinion about the procedure; • Let child make decision: choose what the child likes/wants;	**1**

the life of the child	and request; let the child participate in the procedure; understand the child's thoughts or perceptions about the procedure	• Let the child push the button; • You want to push the button or you want me to do it? • Are you ready? • Can you put your arms up for me? Could you just put your arms here? • Can I see your belly button? • Can you get your mouth open? • Are you hurting today? • Is this going to poke? • You smell that alcohol? • Are you sleepy? You are so sleepy today, aren't you? • Do you feel better? are you okay, baby?	
Being with Being emotionally present to the child	**Sharing feelings:** share joyfulness, happiness, excitement, or celebrations with the child	• I am happy for you; • I am so proud for you; • I felt great today; • We have to celebrate we did it; • I love ya!	**2**
Doing for Doing for the child as he/she would do for oneself	**Protecting:** help child control the painful procedure or give control to the child;	• You let me know, ok; • Mum will hold your hand; • I am here for you; • Mum is here for you;	**3**
	Comforting: entertain and distract strategies (Parent-To-Control)	• Humor; • Telling stories; • Do not think about it/look at me; • Talking things unrelated to the procedure, (i.e., food, toys, pets, other family members et al.); • Rewarding the child by promises; • Ask the child to sleep/nap; • Other comforting verbals, such as "Please calm down";	**4**
Enabling Facilitating the child's passage through life transitions and unfamiliar events	**Informing/explaining:** Give information and explain the procedure related to health history, disease, procedure	• They will flush your port quickly; • Let us get the woody out of your body; • It is the same thing you did before; • You should let the tube put there; • Pull the tube tightly; • She will put the tape on your body; • Now, it gonna be just a little bee sting	**5**
	Validating: Reassure	• It is ok;	**6**

	the child's experience of the procedure and the progress of procedure	• It is almost over; • All done; that is it; it is almost the way out/almost; • I know it is hard; • I know you need help; • I know it hurts; • I know but you have to do it;	
	Supporting/Allowing: guide the child to use coping strategies (Child-To-Control)	• Let us count 1, 2, 3; • Relaxation; • Take a deep breath; • Hold my hands/Pinch me when you feel the needle; • Imagine you are a Spiderman and have the strength;	**7**
Maintaining belief Sustaining faith in the child's capacity to get through an event or transition	**Believing in/holding in esteem:** praise/acknowledge the child; show encouragement to the child	• You are a hero; • Great job; • You are doing great; • You are a brave boy; • You are a sweet heart/good boy; • You have such a beautiful body;	**8**
Non-Caring Showing less parental physical and emotional presence/engagement to the child; leading increasing burdens to the child;	**Burdening by emotions/intrusive questions:** express affective distress (e.g., distress, discomfort, disgust, restless, fear and avoidance)	• I am so anxious/worried/terrified; • I hate this procedure a lot; • Argue with the child; • Are you scared/worried/anxious? • Why do you cry? • Why are you doing that? • What are you crying for?	**9**
	Apologizing: show sorrow and responsibility for the painful procedure	• I am sorry, babe; • I am sorry it will take so long; • I wish I did not hurt you at all; • I will not do this again for you;	**10**
	Criticizing: imply the child's fault or wrong-doings during the procedure	• It is your fault; • You are just a little bitch; • Shut up; • That was not funny at all; • You are making me crazy; • You are a pain;	**11**
Other	**Non-procedure related talk/questions**	• Routine talk/greetings; • School stuff not for distraction; • Conservations unrelated to the procedure agenda; • The whole day plan in the hospital or at home;	

Part II: Nonverbal

Caring: defined as "a nurturing way of relating to a valued other toward whom one feels a personal sense of commitment and responsibility." It includes five domains: Knowing, Being with, Doing for, Enabling and Maintaining Belief.

- Code parent nonverbal behaviors toward their child during port starts into the following categories:

  - Caring nonverbal behaviors: Reflects parent behaviors that attempt to make their child feel understood (Knowing indicators), valued (Being with indicators), safe and comforted (Doing for Indicators, capable (Enabling indicators), and hopeful (Maintaining Belief indicators). All these parental caring behaviors are assumed to relieve child's distress and pain.
    - Knowing: N/A
    - Being With: Being there
    - Doing For: Comforting
    - Enabling: Supporting/allowing
    - Maintaining Belief: Believing in/holding in esteem

  - Non-caring nonverbal behaviors: Reflects parents nonverbal behaviors that make their child feel unsafe and discomforted, incapable, and less hopeful to cope with the procedure. Parental non-caring responses are assumed to increase children's distress and pain.
    - Conveying less availability

  - Neutral nonverbal behaviors: Undefined parental nonverbal and neutral behaviors in the procedure, such as listening to the physician, counseling the physicians.

  - Detail behaviors for each nonverbal category are listed in the following table:

Parental Nonverbal Behaviors

Domain	Subdomain	Specific Code Example	Item #
Nonverbal (6 items)			
Being with	**Being there:** show their emotional presence by eye contact and closeness to them	• Eye contact: a solid >2 seconds eye-to eye contact (Gaze); • Distance close enough to touch the child;	**1** **2**
Doing for	**Comforting:** entertain and distract strategies (Parent-To-Control)	• Playing with the child; • Using stuff animals or toys; • Playing with video games/cards;	**3**

Enabling	**Supporting/allowing:** providing comforting body behaviors	• Preparing the child; give the mask; put up or take off clothes; help with the procedure toward the child; check and clean the port site; lift his arms; give water; • Touch; hugging; kissing; cuddling; holding child hand; wiping child's tears; patting butt; • Positioning; repositioning; sitting on the laps;	**4**
Maintaining belief	**Believing in/holding in esteem**	• Hand claps; • High five;	**5**
Non-Caring	**Conveying less availability**	• Distance too far to touch; • Playing with their phone; • Ignoring the child's talk; • Let the child alone;	**6**

Part III: Emotional

Caring: defined as "a nurturing way of relating to a valued other toward whom one feels a personal sense of commitment and responsibility." It includes five domains: Knowing, Being with, Doing for, Enabling and Maintaining Belief.

- Code parent emotional experiences toward their child during port start into the following categories:

  - Caring emotions: Reflects parent emotions that attempt to make their child feel understood (Knowing indicators), valued (Being with indicators), safe and comforted (Doing for Indicators, capable (Enabling indicators), and hopeful (Maintaining Belief indicators). All these parental caring emotions are assumed to relieve child's distress and pain.
    - Knowing: N/A
    - Being With: Sharing Feelings
    - Doing For: N/A
    - Enabling: N/A
    - Maintaining Belief: Maintaining a hopeful attitude

  - Non-caring emotions: Reflects parent emotions that will make their child feel unsafe and discomforted, incapable, and less hopeful to cope with the procedure. These non-caring emotions are assumed to increase child's distress and pain.
    - Burdening by emotions

  - Neutral: Undefined parental emotional that are neutral in the procedures, such as keeping relaxed and calming down.

- Detail behaviors for each emotional category are listed in the following table

Parent Emotional Behaviors

Domain	Subdomain	Specific Code Example	Item #
Emotional (1 item with three levels)			
Caring		• Warm, friendly, loving, tender; • Happy, laughing, joking, joyful;	**1**
Neutral		• Matter of fact, neutral;	**2**
Non-Caring		• Anxious, nervous, scared, fear; • Frustrated, depressed, exhausted, lost, sad; • Angry, hostile, annoyed, irritated;	**3**

APPENDIX 5. THE P-CaReSS CODING GUIDELINE

1. General Coding Guideline

Targeted Person	Code the identified **Parent** Verbal/Nonverbal/Emotional Behaviors (using P-CaReSS) and **Child** Verbal and Behavioral Distress (using K-CCD subscale). **The list of targeted parent and child** for each video has been updated.
Coding Time Frame	All the coding should follow the **time frame** (pre, during and post) as listed in the video list.
Coding strategy	**Frequency** for Parent verbal behaviors; **Duration** for parent Nonverbal behaviors; **Global code** for parent Emotional Behaviors; **Frequency** for Child Verbal Distress and **Duration** for Behavioral Distress;
Coding Principle	Each **verbal statement** should be coded as long as it is clearly auditable. For a continuous sentence, each auditable statement should be coded separately. For these verbal statements that are hard to distinguish (i.e., voice too low to hear, covered by other staff's voice or environmental noise), no code is necessary; for the **closely connected or very short verbal statement**, the addressed section should be coded, e.g., "It is almost over, ok (coded as **validating**)", "It is almost done and you should calm down (coded as **validating**)" For the duration codes, 2s coder response time are allowed so that if one behavior, e.g., crying, happens with less than 2s offset, it can be continuously coded and no need to stop.
Coder Requirement	**Trained coders** follow the coding system during the coding

2. Specific Coding Guideline

Verbal codes	**Verbal codes** are listed with clear examples and all the distinguishable statements should be given different codes except the statements unassociated with the procedures, i.e., unrelated to procedures. If parent talks about the same thing in several consecutive verbal statements (e.g., read to book or telling a story), the code will be given only once at the beginning. For these parental keep talking the same words continuously, once code at the beginning (i.e., what? What? What?). For these short verbal statements, if parent uses the same verbal statements several times (i.e., you will be ok!), just code at the beginning of the first one, and then code it only when both verbal statements beyond 5 seconds. **Avoiding assumption** is focusing on to understand the child from their own perspective; **information giving/explaining** is to give information and introduce the child about the situations in front of him/her. For the **verbal Supporting/Allowing**, all the codes should focus on the

	listed behaviors, such as relaxation, deep breath; all the other related **Comforted behaviors** should be coded as **Comforting**, such as "Please calm down", "You must be sleepy", "Please take a nap"; For the **Criticizing**, only focus on the content of the Verbal Statement, no need to predict based on the emotional expression. Mostly this verbal statement indicates fault with the activities, products, or attributes of the child. **Non-procedure related behaviors**, such as research participation and family events, will not be coded. During the pre-, during, and post-procedure, all the caring or behaviors should be coded based on the coding system. These off-topic or irrelevant verbal statements should be coded in this category.
Nonverbal	**Eye contact** is defined as when the parent and child look at each other's eyes at the same time. In this study, only a solid >2 seconds eye-to eye contact is coded (refers to Gaze from Manson, 2011). Due to the different eagles of camera during the video recording, it is assumed as "eye contact" when two person's eyes are looking at each other in the same eagle even if we cannot see that from our direction. **NV Supporting/Allowing** includes all kinds of behaviors, such as parent preparing the child, positioning the child, touching the child et al. Please code it as long as one of these behaviors exists. **Distance close or Less Availability** indicates that the parent body is close enough to touch any part of the child, such as head, legs or trunk.
Emotional	**Caring, Non-Caring and Neutral feelings** describe the parent emotions toward their child rather than toward health care providers or other family members. The global judgement of Parent Emotional Status should be based on parental facial expressions, body language, and physical behaviors and verbal behaviors.
Child distress	In terms of the child distress, code it as **Behavioral Distress** if you cannot clearly hear what the kids saying/talking about.

APPENDIX 6. INTER-RATER RELIABILITY AS MEASURED BY PERCENT AGREEMENT OR KAPPA VALUE BETWEEN TWO CODERS

Participant ID	Verbal										
	AA	SF	PR	CO	BE	IE	VA	SA	CR	AP	BI
1	—	—	—	—	—	—	—	—	100.00	—	—
2	100.00	—	—	100.00	—	—	—	—	—	—	—
3	57.10	—	—	40.00	100.00	100.00	31.30	100.00	—	—	—
4	—	—	—	23.10	—	20.00	37.50	100.00	—	—	—
5	—	—	—	—	—	—	—	—	—	—	—
6	100.00	—	—	100.00	—	75.00	100.00	50.00	—	—	—
7	—	—	—	75.00	—	100.00	40.00	0.00	—	—	—
8	83.30	—	—	100.00	100.00	100.00	—	—	—	—	—
9	100.00	—	—	100.00	50.00	100.00	100.00	100.00	—	—	100.00
10	—	—	—	—	—	—	—	—	—	—	—
11	100.00	—	—	—	—	—	—	—	—	—	—
Avg. item	90.07	NA	NA	76.87	83.33	82.50	61.76%	70.00	100.00	NA	100.00
Kappa	—	—	—	—	—	—	—	—	—	—	—
Avg. total											

Participant ID	Nonverbal						Emotional	Average Sample
	EC	DC	NCO	NSA	NBE	LA	CARE	
1	41.60	—	—	—	—	99.70	100.00	85.33
2	—	99.90	—	100.00	—	95.10	0.00	82.50
3	82.80	99.60	17.70	98.90	—	68.90	100.00	74.69
4	—	99.40	96.30	99.70	—	—	100.00	72.00
5	—	—	—	—	—	99.70	100.00	99.85
6	—	99.40	—	96.20	—	61.20	100.00	86.87
7	—	99.10	—	96.50	—	57.20	100.00	70.98
8	—	99.40	—	96.90	—	—	100.00	97.09
9	—	99.70	—	99.70	—	—	100.00	94.94
10	—	98.20	—	60.00	—	99.00	100.00	89.30
	—	100.00	—	100.00	—	—	100.00	100.00
Avg. item	62.20	99.41	57.00	94.21	NA	82.97	90.91	86.89
Kappa	—	—	—	—	—	—	0.81	—
Avg. total								82.23%

Note: AA = Avoiding assumptions/seeking cues; AP = Apologizing; BE = Believing in/holding in esteem; BI = Burdening by emotions/intrusive questions; CO = Comforting; CR = Criticizing; DC = Distance close to touch; EC = Eye contact; IE = Informing/explaining; LA = Conveying less availability; NBE = Believing in/holding in esteem; NCO = Comforting; NSA = Supporting/allowing; PR = Protecting; SA = Supporting/Allowing; SF = Sharing feelings; VA = Validating

APPENDIX 7. EXAMPLES OF SAS/GSEQ CODES FOR DATA ANALYSIS

Study Aim 1

Shapiro-Wilk test

```
proc univariate data=carecmh1 normal;
var PPD PCHD PCHC MSPD MSCHD MSCHC CCHD OCHC OCHD;
by time;
run;
```

Mixed modeling with generalized estimating equations (GEE)

```
data caregee1;
set mylib.caregee;
run;

proc genmod data=caregee1 descending;
class id time;
model T1D1=T1B1 Time
/ dist=binomial link=logit;
repeated subject=id
/ within=time type=exch corrw;
lsmeans time / adjust=tukey;
run;

proc genmod data=caregee1 descending;
class id time;
model T1D2=T1B2 Time
/ dist=binomial link=logit;
repeated subject=id
/ within=time type=exch corrw;
lsmeans time / adjust=tukey;
run;

proc genmod data=caregee1 descending;
class id time;
model T1D3=T1B3 time
/ dist=binomial link=logit;
repeated subject=id
/ within=time type=exch corrw;
lsmeans time / adjust=tukey;
run;
```

Friedman's Test

```
Data carecmh1;
set mylib.carecmh;
```

```
run;

proc sort;
by time;
run;

proc freq data=carecmh1;
  tables ID*time*T1_1S
  / CMH Score=rank;
run;

proc freq data=carecmh1;
  tables ID*time*T1_2S
  / CMH Score=rank;
run;

proc freq data=carecmh1;
  tables ID*time*T1_3S
  / CMH Score=rank;
run;
```

Study Aim 2

Mixed modeling with GEE (P-CaReSS Item & Parent and Child Well-being)

```
data caregeecat;
set mylib.caregee2;
run;

proc genmod data=caregeecat descending;
class id time;
model PPD_CAT=T1_1S Time
/ dist=binomial link=logit;
repeated subject=id
/ within=time type=exch corrw;
run;

proc genmod data=caregeecat descending;
class id time;
model PPD_CAT=T1_2S Time
/ dist=binomial link=logit;
repeated subject=id
/ within=time type=exch corrw;
run;

proc genmod data=caregeecat descending;
class id time;
```

```
model PPD_CAT=T1_3S Time
/ dist=binomial link=logit;
repeated subject=id
/ within=time type=exch corrw;
run;
```

Mixed modeling with GEE (P-CaReSS Domain and Parent and Child Well-being)

```
data caregeedomain;
set mylib.caregee2;
run;

proc genmod data=caregeedomain descending;
class id time;
model PPD_CAT=Vdomain3 Time
/ dist=binomial link=logit;
repeated subject=id
/ within=time type=exch corrw;
run;

proc genmod data=caregeedomain descending;
class id time;
model PPD_CAT=vdomain5 Time
/ dist=binomial link=logit;
repeated subject=id
/ within=time type=exch corrw;
run;

proc genmod data=caregeedomain descending;
class id time;
model PPD_CAT=vdomain6 Time
/ dist=binomial link=logit;
repeated subject=id
/ within=time type=exch corrw;
run;
```

Study Aim 3

Create SDS file from the StudioCode Output Data

1. Open the "Edit List File (Studiocode Output)" and delete "The Last Three Columns", and move "Category" into the first column

2. Delete the first row with all the names of variable

3. Replace all "., /, (2) with the _" and then replace "_ _" with "_"

4. Split the second and third column into different columns, “DATA”—“Text to columns”—“Delimited”—“Tab and other “:””—“NEXT and Finish”

5. Only keep the Hour, min and second (remember that the entire data format should be consistent such as 0:59:20 or 1:1:23)

6. Add the “,” between the first column and the first column for the time; add “:” between each time period for the start and end time; and add the “-” between the start and end time

7. Open the edited file in the Notepad++, click “Search-Replace”, Find what “\t” and replace with “nothing”, replace all, search mode click “Extended (\n,\t,\r….)”, then save it

8. Add
“Timed
<seconds>
Apologizing Av_Assumption Behavioral_Distress Believe_in_Esteem Burden_Intrusive Caring Comforting Criticizing Distance_Close Eye_Contact Info_Explain Less_Availability NV_Belief NV_comforting NV_Supp_Allow Protecting Sh_Feelings Support_Allow Validating Verbal_Distress;” at the beginning;
A “/” at the end

9. Then change the “file extension” into “SDS”

10. Then open it in the GSEQ File and format it

Create 5-second Time Window

WINDOW x = a),a)+5

would create a new code x attached to 5 seconds after every occurrence of code a, i.e.:

```
-----aaaaaaaa-----------a------------aaaaaa----------------
-------------xxxxx-------xxxxx--------------xxxxx-----------
```

A command like:

WINDOW y = (a,(a+4

would create a new code y attached to the first 5 seconds of every occurrence of code a, i.e.

```
-----aaaaaaaa-----------a------------aaaaaa----------------
-----yyyyy--------------yyyyy--------yyyyy-----------------
```

For more info, see the help about WINDOW in the GSEQ Help menu: How to use GSEQ > GSEQ procedures > Modify MDS File > Window command

Data Analysis in the GSEQ File

1. Open the SDS file in the GSEQ software

2. Compile to SDS file and create MDS file; check about all the warning in the compile file

3. Run---Plot MDS file

4. Check about the results to see what is happening