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Parent Caring Response Scoring System (P-CaReSS): Development and Psychometric Evaluation in the Context of Childhood Cancer-Related Port Starts

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Abstract

Rationale—Multiple observational coding systems have been developed and validated to assess parent-child interactions during painful procedures. Most of these coding systems are neither theory-based nor do they well represent parent nonverbal behaviors.

Aims—Develop the Parent Caring Response Scoring System (P-CaReSS) based on Swanson's Theory of Caring and test its psychometric properties in children in cancer port starts.

Methods—A hybrid approach of inductive and deductive coding was used to formulate the preliminary observational codes for the P-CaReSS. Twenty-nine children, each with one video-recording of port start available, were selected from the parent study (R01CA138981) to refine the P-CaReSS, train coders, and test inter-rater reliability. Videos of another 43 children were used to evaluate the construct validity of P-CaReSS. Percent agreement and Cohen's kappa were used to present the inter-rater reliability. Spearman rank-order correlations were used to report the construct validity.

Results—The 18-item P-CaReSS includes three types of parent behaviors: verbal, nonverbal, and emotional behaviors. These parent interaction behaviors comprise 5 caring domains –knowing, being with, doing for, enabling, and maintaining belief –and one non-caring domain. On average the percent agreement was 0.82 for the P-CaReSS overall, with average percent agreements above

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Ethical Approval

The Institutional Review Board (IRB, IRB#143111) of the University of North Carolina at Chapel Hill, North Carolina reviewed and approved the study protocol relying on an external IRB approval (IRB#033309B3E) at Wayne State University, Detroit, Michigan.

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0.80 for both verbal and nonverbal behaviors. Kappa coefficient was 0.81 for the emotional behavior. The behavioral codes in the P-CaReSS showed significant correlations with independent ratings of parent distress, child distress, and child cooperation.

Conclusions—The P-CaReSS is a promising tool that can be used to evaluate parent verbal, nonverbal, and emotional behaviors during cancer-related port starts. This observational tool can be used to guide the development of nursing interventions to help parents caring for their child during cancer procedures.

Keywords

Parent-child interaction; measure; caring; painful procedure; psychometric property

Introduction

Approximately 12, 400 children are diagnosed with cancer each year in the United States (1, 2). Children 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 a variety of painful procedures including lumbar punctures (LPs), bone marrow aspirations (BMAs), and port start which is used to establish intravenous access through which chemotherapies and supportive care agents can be delivered that day or in the near future (1, 3). Children reported that these painful procedures can be more traumatic than cancer itself (4). For children treated for cancer, parent interaction behaviors can interactively impact child pain and distress in relation to invasive procedures. Blount et al. investigated parent-child interactions during LPs and BMAs and found that parent coping-promoting behaviors, including humor, commands to use coping strategies, and nonprocedural talk, can reduce child distress and increase child coping levels (5, 6). In contrast, parent distress-promoting behaviors, including verbalization of empathy, criticism, apology, giving control to the child, and reassurance, can promote child distress during LPs and BMAs (5, 6).

Parent interactions with their child during painful procedures including in the context of childhood cancer have been widely studied but the findings have been inconsistent and difficult to explain (7, 8). These inconsistent findings can be explained in part by the use of various observational systems to code parent interaction behaviors and by the lack of theoretical bases for the development of extant coding systems, which could set the underpinnings to explain these results. Consistent use of a reliable and valid interaction analysis system (IAS) can advance the study of parent interaction behaviors and the development, testing, and implementation of interventions to improve the experience and outcomes for both the parent and the child.

Multiple IASs such as the Child-Adult Medical Procedure Interaction Scale-Revised (CAMPIS-R) (9) and CAMPIS-Short Form (CAMPIS-SF) (6) are available for assessing parent-child interactions during medical painful procedures. Most of the extant IASs have been shown to have acceptable levels of inter- and intra-rater reliability, support for validity, and clinical relevance (10). However, they have weaknesses, including lacking a theoretical model (6, 9), underrepresenting parent nonverbal behaviors (11), and being too lengthy for

use in practice (5, 10). The development and validation of a succinct yet comprehensive IAS is essential to develop evidence-based assessments and interventions to help children cope with distressing and painful medical procedures. Furthermore, building this IAS on an explicit theoretical model can guide the development of behavioral codes, the operational definition for each code, and the selection of theory-related variables for use in establishing evidence for the validity of the IAS.

The purpose of this study was to describe the development, refinement, and preliminary psychometric evaluation of a new IAS referred to as the Parent Caring Response Coding System (P-CaReSS). The P-CaReSS differs from existing observational IASs in that the codes represent the conceptual domains of caring as defined in Swanson's Theory of Caring (12, 13). The specific aims of this study 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 (i.e., inter-rater reliability [IRR]); and (3) examine construct validity of the P-CaReSS using the relationships between the behavioral codes in the P-CaReSS and three global ratings coded by various raters: parent distress and child cooperation (rated by parent, medical staff, and trained observer) and child distress (rated by parent, medical staff, trained observer, and child).

Swanson's Theory of Caring is a middle-range theory that shows less abstraction, addresses specific phenomena or concepts, and reflects meanings in practice; this theory has been extended to understand parent perceptions and behaviors in taking care of their child in clinical care situations such as congenital heart disease (14) and brain trauma (15). Therefore, Swanson's Theory of Caring provides a suitable basis for the development of observational coding systems in understanding parent caring behaviors during cancer-related painful procedures (16, 17). In the theory, Swanson has defined the concept "caring" with five well-defined theoretical domains: maintaining belief (i.e., "sustaining faith in the other's capacity to get through an event or transition and face a future with meaning"); 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"); and enabling (i.e., "facilitating the other's passage through life transitions and unfamiliar events") (12, 13). Caring interactions between parents and child during stressful events such as cancer painful procedures can beneficially affect the caregiver and the care recipient (18–20), thus reducing parent distress and child distress and increasing child cooperation. Because parents are human, not all parenting behaviors during their child's painful procedures can be constructed 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 (9, 21). 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 such as less pain and distress but more satisfaction.

Based on Swanson's theory (i.e., five caring domains and family member well-being [e.g., self-efficacy and satisfaction]), the variables in this study (i.e., parent caring/non-caring

behaviors, parent distress, child distress and child cooperation) are shown in Figure 1, which describes how Swanson's theory is used as the conceptual model when designing and testing the P-CaReSS. The variables in this study were primarily used to understand how parent interact with their child during cancer painful procedures assessed by the P-CaReSS and how child responses to the parent interaction behaviors assessed by the Revised Wong-Baker Faces Scale.

Materials and methods

Design

This study used a prospective observational design. The IAS development process (22) was guided by Swanson's Theory of Caring (16) and a hybrid approach of inductive and deductive coding was used to formulate the preliminary observational codes for the P-CaReSS (23). Two sources of observational data were used: a publicly available documentary film called "The Waiting Room" (24) and two subsamples from data originally collected as part of a grant titled "Resources, parent-child communication and adjustment to pediatric cancer" (R01CA138981, PI: L. Penner), referred to hereafter as "the parent study". The Institutional Review Board (IRB) of XXX reviewed and approved the study protocol relying on an external IRB approval at XXX.

Sample

Data source 1—Six video clips were extracted from the "The Waiting Room" (24). These video clips show a pair of parents interacting with their 9-year-old daughter as she underwent painful (e.g., venipuncture) and frightening (e.g., computerized axial tomography scanning) procedures during an Emergency Room visit. These video clips were used to generate the pool of behavioral codes for the P-CaReSS.

Data source 2—The present study is part of a larger longitudinal parent study (R01CA138981) that collected data from 2009 to 2015 at two large children's hospitals in the United States. The study protocol was reviewed and approved by the hospitals' Institutional Review Boards (IRBs) and the university affiliated with one of the hospitals. The primary aim of the parent study was to identify factors that place families at risk for psychosocial problems due to the stress of cancer-related treatment procedures. Families were eligible if (1) the child was between 3 and 12 years; (2) the child had been diagnosed with cancer at least 1 month but no more 18 months before study entry and was receiving port starts, LPs, and/or BMAs; and (3) parent and child were able to speak and the parent could read English well enough to provide consent and complete the questionnaires.

In this IAS development study, two subsamples were chosen from the parent study sample and only children with video recording of port start procedure were used in this study ($n = 83$). For the first subsample, 29 parent-child dyads were chosen because only one port start procedure had been video-recorded and these videos were used to refine the P-CaReSS (13 videos), train data coders (5 videos), and test the IRR (11 videos). For the second subsample, 43 parent-child dyads were chosen because at least two of their port start procedure had been

video-recorded and these videos were used to test the relationships between the P-CaReSS and three individual-reported outcomes: parent distress, child distress, and child cooperation.

Instrument Development Process

The P-CaReSS was developed and tested in accordance with the IAS development guidelines (22, 25). This process includes the following five steps:

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

Deciding the feature of the codes—Social-based codes were developed in the P-CaReSS. Bakeman and Gottman have established two types of observational codes: physical-based and social-based codes (26). Physical-based codes apply to explicit physical actions such as the parent touching the child or the child crying; social-based codes apply to study perceptions of a social process. Painful treatment procedures occur in a social context wherein child and parents engage in a social process in which parent behaviors have meaning to their child. 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 behavior) and exhaustive (i.e., there is some code for every behavior) according to previous literature (26, 27).

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 (23). The observational codes were inductively generated from “The Waiting Room” (24); 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 regular communications with the theorist Kristen Swanson. Then, the inductively derived behavioral codes were deductively assembled into domains informed by Swanson’s Caring Theory. The challenges of using this theory in the development of the behavioral codes were discussed with the theorist to identify strategies to address them. For instance, both the category definitions (e.g. “doing for” or “enabling”) 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.

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 extant parent-child interaction measures. All the operational definitions have to meet the following criteria: objectivity, clarity, and completeness (25).

Refining the system—The behavioral codes and operational definitions were refined by applying them to code video-recordings of children undergoing cancer treatment-related port starts (n = 13). This sample of children was randomly selected from a subsample of

children with one video-recorded port start in the parent study ($n = 29$). Based on this initial application, all the behavioral codes were refined, and the P-CaReSS and its coding manual were prepared for preliminary psychometric evaluation.

Preliminary Psychometric Evaluation

The preliminary psychometric evaluation process included the following four steps:

Training coders—The first author and one PhD-prepared coder were trained by a laboratory 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. Five randomly selected videos were used to train the second coder using the P-CaReSS by the first author and coding results were compared between both coders for each video. The second coder was considered sufficiently credentialed to conduct coding when she achieved 80% agreement with the first author's coding (25). After the second coder was trained to use the observational P-CaReSS, both coders used the P-CaReSS to code each video independently. Both coders met daily to resolve coding disagreements during the training period. The training protocol and coding manual of the P-CaReSS can be requested from the first author.

Coding—After the second coder was credentialed, both coders rated the video-recorded data using StudioCode[®] software. The timed-event coding method was used to capture frequency, duration, and timing of behavioral codes (26). For the verbal behaviors, onset times of behaviors were recorded in the StudioCode[®] timeline, thereby providing frequency data for verbal “event” codes. As nonverbal behaviors can not only co-occur with verbal and emotional behaviors but also be of extended duration, the duration time for these behaviors were recorded as “state” codes, yielding both a 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 video-recorded treatment procedure was given a global rating consisting of one of three levels. The coders met weekly during the coding period to review coding and reach consensus on disagreements through discussion and reviewing evidence of the videos.

Inter-rater Reliability analysis—To estimate the reliability between trained coders (i.e., IRR), either the percent agreement or Cohen's kappa was calculated. A PhD-prepared laboratory research manager programed the IRR in the StudioCode[®]. Typically, a random sampling of 10% – 30% of the video data is adequate to examine IRR when there is more than one coder (28). In this study, the video data from 11 participants (13%) with port start video in the parent study ($n = 83$) were used to calculate the IRR. Point-by-point percent agreement was computed to present the IRR for the verbal 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 (25, 29); and Cohen's kappa was estimated as the measure of IRR for the codes that represent emotional behavior as it is a categorical variable (Formula b) (26). The IRR is considered to be at an adequate level when the measure value is above 0.80 (25).

$$\frac{\text{Number of Agreements}}{\text{Number of Agreements} + \text{Number of Disagreements}} \times 100 \quad (\text{Formula a})$$

=Percent Agreement

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

=Kappa value

Construct Validity analysis—Given non-normal distributions, Spearman rank-order correlations were used to examine the construct validity using the relationships between parent interaction behaviors coded using the P-CaReSS and the global ratings of parent distress and child cooperation (rated by parent, medical staff, and trained observers who watched video-recordings after procedures) and child distress (rated by parent, medical staff, trained observers, and children themselves). The revised Wong-Baker Faces scale was used to rate parent distress, child distress, and child cooperation during treatment procedures (30). 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) (31). Its total score ranges from 1 to 7. All rating scales show good reliability in previous studies.

Results

P-CaReSS

The P-CaReSS comprises 18 items that describe three types of parent interaction behaviors (Table 1): verbal (11 items, e.g., avoiding assumptions/seeking cues; protecting, informing and explaining), nonverbal (6 items, e.g., eye contact, distance close enough to touch and supporting/allowing), and emotional (1 item with three levels, i.e., caring [positive], neutral, and non-caring [negative]). 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), and maintaining belief (2 items)—and one non-caring domain (4 items). Parents are human and can experience fear and other negative emotions, so not all parenting behaviors during their child’s painful procedures can be constructed as caring for the child but rather the parent’s efforts to control their own intense emotions. A non-caring domain was added based on previous literature and existing measures (11, 32). This non-caring domain can account for parent behaviors that reflect their escalating distress and diminishing capacity to engage in prosocial behaviors to promote their child’s wellbeing. Emotional behavior is designed to capture parent emotion state during cancer painful procedures (27).

Reliability

Participants—Eleven parent-child dyads with one video-recorded port start were selected from the parent study to examine the IRR of P-CaReSS. Table 2 presents information about these participants.

Inter-rater reliability analysis—As shown in Table 3, 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 good IRR to assess parent interaction behaviors during cancer treatment port starts.

Validity

Participants—Forty-three parent-child dyads with 2–3 video-recorded port start procedure were selected from the parent study to establish preliminary support for the construct validity of the P-CaReSS. Table 4 provides information about these participants.

Construct validity analysis—Spearman's correlation coefficients were reported between the behavioral codes in the P-CaReSS and measures of three theoretically relevant variables: parent distress, child distress, and child cooperation (Table 5).

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) ($r_s = 0.34 - 0.74$, $p < 0.05$) and less availability was negatively and significantly correlated with child distress as rated by at least one type of rater ($r_s = -0.34 - -0.58$, $p < 0.05$). Three caring behavioral codes (i.e., sharing feelings, comforting, nonverbal believing in/holding in esteem) and one non-caring behavioral code of the P-CaReSS (i.e., apologizing) were not significantly correlated with any rating of child distress.

Nine behavioral codes of the P-CaReSS were positively and significantly correlated with parent distress as rated by at least one type of rater ($r_s = 0.34 - 0.63$, $p < 0.05$) and less availability was negatively and significantly correlated with parent distress as rated by at least one type of rater ($r_s = -0.52 - -0.58$, $p < 0.05$). Finally, 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) ($r_s = -0.34 - -0.78$, $p < 0.05$) and parent less availability was positively and significantly correlated with child cooperation as rated by at least one type of rater ($r_s = 0.34 - 0.43$, $p < 0.05$).

Discussion

The purpose of this study was to develop and test a theory-based IAS (i.e., P-CaReSS) that captures parent interaction behaviors toward their child during cancer treatment procedures involving port starts. The new P-CaReSS coding system was developed based upon Swanson's Theory of Caring (16) to categorizes parent behaviors during children's port starts into caring and non-caring domains. Previous literature suggested that verbal, nonverbal, and emotional interaction behaviors can influence patient experience and responses (e.g., pain and distress) during painful procedures (11, 27, 32). Thus, this tool is designed to capture 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 (9, 10). The P-CaReSS is a novel tool developed with

clear theoretical basis, which can guide the development and testing of interventions to help children and their parents cope with painful procedures from a caring perspective.

A recent systematic review found that more than 30 factors can influence child distress level during painful procedures (33), and parents' interaction with their child during procedures are significant predictors of child distress. 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 serve as a guide for theory-based assessments and tailored interventions to enhance parent positive interaction behaviors, thereby improving the treatment experience for children by lowering levels of child pain and distress and increasing levels of child cooperation.

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 data, previous literature, and extensive clinical observations; these resources enrich the pool of parent behavioral codes and increase 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 (22, 26). Consequently, this study provides an exemplar for the development of an observational coding system based on a middle-range theory and current observational instrument development guidelines.

The P-CaReSS shows acceptable to excellent reliability. The average percent agreements for trained coders were above 80% for verbal, nonverbal, and emotional domains, as well as for the P-CaReSS overall. The emotional behavior showed an excellent kappa value in this study ($\kappa = 0.81$). All of these values provide support that the P-CaReSS is a reliable measure that can be used to capture parent interaction behaviors during cancer 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 differ from previous studies, which have found that apology is one behavior that is frequently used by parents and healthcare providers during painful procedures (9, 30). There may be several explanations for the rare occurrences of these verbal and nonverbal behaviors in this study. First, a 5-minute slice during port starts was selected from each video for the IRR testing, and it is possible that the slices may not have reflected the absolute presence of these behaviors across the entire procedure. Second, the P-CaReSS was designed to assess parent interaction behaviors; whereas other coding systems such as the CAMPIS-R and CAMPIS-SF were developed to assess adult-child interactions (whether parents and healthcare staff interact with children). Chorney and colleagues have found that parents used less apologizing behaviors than nurses, which may account for the lack of apologizing behaviors in this study (34). Although these four parent behaviors did not occur in our study sample, we still suggest keeping and empirically testing these behaviors in a larger sample in future research because these behaviors were built on theoretical basis and previous literature.

Significant correlations between the behavioral codes in the P-CaReSS and multi-rater global ratings of parent and child distress and child cooperation provide preliminary support for the construct validity of the P-CaReSS. Behavioral codes in the P-CaReSS (e.g., verbal behaviors of protecting, supporting/allowing, and nonverbal support/allowing) showed positive correlations with parent distress and child distress and negative correlations with child cooperation. These findings seem to be opposite to previous studies (6, 35), which indicated that more parent coping-promoting behaviors (e.g., humor, nonprocedural talk, and commands to use coping strategies) 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 higher 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 has indicated caring occurring as a consequence of distress experienced by the caregiver, in which the caregiver acts to show more empathic concerns or discharge their own distress and discomfort or (36–38). Thus, the P-CaReSS shows adequate preliminary reliability and validity for use during cancer treatment–related port starts.

This study has theoretical and methodological strengths. First, the P-CaReSS is an observational coding system that is developed based on Swanson's Theory of Caring (12), which has been widely used in the instrument development and theory-based interventions (17, 39). Theory of Caring provides a means to build new knowledge based on current understanding of parent-child interactions during painful procedures with coherent and theoretical directions. Swanson's Theory of Caring was selected as the conceptual model owing to its characteristics of middle-range theory (e.g., less abstraction and easy translation into practice) and wide use in understanding parent perceptions and behaviors toward their child in clinical care situations (14, 15, 40). Second, the newly developed P-CaReSS contributes to parent-child interaction studies by adding new codes regarding parent nonverbal and emotional behaviors during procedures. For example, the P-CaReSS lists some parent behaviors rarely described in previous studies such as personal distance and eye contact and offers evidence for the value of these nonverbal behaviors in relieving child's levels of pain and distress during painful procedures. Additionally, 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 (41, 42). This study provides a new tool to assess parent caring behaviors so that relevant interventions can be designed to promote both child's well-being (e.g., less pain and distress, more cooperation, and higher quality of life) and parental well-being (e.g., less distress, more satisfaction, and higher quality of life) through the journey of cancer treatment.

This study has several limitations. First, preliminary psychometric evaluation of the P-CaReSS was performed in a sample of children undergoing cancer treatment port start procedure. It is not clear if the validity and reliability of the P-CaReSS will generalize to other treatment procedures such as LPs and MBAs. The majority of parents were female for the inter-rater reliability and construct validity analyses, limiting its use in fathers of children with cancer. Second, a thin-slice approach (i.e., 5 minutes) was applied in this study. Although this approach has been well-validated for use in the communication studies (34,

43), no current empirical or theoretical guidelines exist regarding how to choose the slices on parent behavior during painful procedures. Thus, it is possible that results could vary if thin slices were selected across all phases of the procedures (i.e., pre, during, and post) rather than from the procedure alone. It is also possible that results may differ if other selection procedures are used (e.g., every other 60 seconds). Future research on the differences across selection procedures can provide further evidence of the psychometrics of P-CaReSS. Last, the validity of the P-CaReSS was examined in terms of its correlations with parent distress, child distress, and child cooperation. While these ratings by multiple raters provide methodological strength, the concurrent and predictive validity of the P-CaReSS could be further strengthened by comparisons with other observational measures such as the CAMPIS-R (9) and Parent Communication Typology (30).

Conclusions

This study described the development of the observational P-CaReSS coding system using the hybrid approach of inductive and deductive coding and provided the preliminary evidence of its reliability and validity. The newly developed 18-item P-CaReSS captures not only parent verbal behaviors but also parent nonverbal and emotional behaviors. The psychometric properties of the coding system were tested on a sample of children undergoing painful and distressing cancer treatment procedures. IRR was assessed using percent agreement and Cohen's kappa value and its validity was tested through correlational analyses with validated measures of parent and child distress and child cooperation during treatment procedures. This study further demonstrates the feasibility of developing an observational tool based on a middle-range theory – Swanson's Theory of Caring. In summary, the P-CaReSS is a promising observational coding system that can be used to evaluate parent interaction behaviors during children's cancer treatment procedures so that caring theory-based interventions can be designed to improve children's and parents' well-being such as less pain and distress and higher quality of life. The psychometric properties of the P-CaReSS should be further tested in a sample of children undergoing other painful and distressing cancer treatment procedures.

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Figure 1.
Swanson's Theory of Caring and relationships to the study variables

Table 1**Parent Caring Response Scoring System (P-CaReSS)**

Domain	Specific Item
<i>Verbal (11 items)</i>	
Knowing: Striving to understand an event as it has meaning in the life of the child	Avoiding assumptions/seeking cues
Being with: Being emotionally present to the child	Sharing feelings
Doing for: Doing for the child as he/she would do for oneself	Protecting Comforting
Enabling: Facilitating the child's passage through life transitions and unfamiliar events	Informing/explaining Validating Supporting/allowing
Maintaining belief: Sustaining faith in the child's capacity to get through an event or transition	Believing in/holding in esteem
Non-Caring: Showing less parental physical and emotional presence/engagement to the child; leading increasing burdens to the child	Burdening by emotions/intrusive questions Apologizing Criticizing
Other	Non-procedure related talk/questions
<i>Nonverbal (6 items)</i>	
Being with: Being emotionally present to the child	Eye contact Distance close enough to touch
Doing for: Doing for the child as he/she would do for oneself	Comforting
Enabling: Facilitating the child's passage through life transitions and unfamiliar events	Supporting/allowing
Maintaining belief: Sustaining faith in the child's capacity to get through an event or transition	Believing in/holding in esteem
Non-Caring: Showing less parental physical and emotional presence/engagement to the child; leading increasing burdens to the child	Conveying less availability
<i>Emotional (1 item)</i>	
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

Table 2

Participants' descriptive statistics at baseline for the inter-rater reliability analysis (n = 11)

Variable	Mean (SD)	Range
<i>Child</i>		
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)	
Race, n (%)		
White	9 (81.8)	
African American	2 (18.2)	
Diagnosis, n (%)		
Leukemia	11 (100)	
<i>Parent</i>		
Age, year	30.7 (5.0)	23–37
Gender, n (%)		
Female	10 (90.9)	
Male	1 (9.1)	
Race, n (%)		
White	8 (72.7)	
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, n (%)		
high school	3 (27.3)	
> High school	8 (72.7)	
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)	

Table 3

Inter-rater reliability for 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		

NA = not applicable; P-CaReSS = Parent Caring Response Scoring System

*
1 behavioral code with IRR < 0.7;**
2 behavioral codes with IRR < 0.7

Table 4

Participants' descriptive statistics at baseline for the validity analysis (n = 43)

Variable	Mean (SD)	Range
<i>Child</i>		
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 (%)		
Leukemia	28 (65.1)	
Lymphoma	3 (7.0)	
Solid Tumor	8 (18.7)	
Other cancer	4 (9.2)	
Race, n (%)		
White	31 (72.1)	
African American	8 (18.6)	
Other	4 (9.3)	
<i>Parent</i>		
Age, year	34.4 (7.1)	20–54
Gender, n (%)		
Female	34 (79.1)	
Male	9 (20.9)	
Race, n (%)		
White	32 (74.4)	
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 (%)		
High school	12 (28.0)	
> High school	31 (72.0)	
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)	

Variable	Mean (SD)	Range
\$60, 000 ~ \$100, 000	10 (23.3)	
Greater than \$100, 000	6 (14.0)	

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Table 5
Spearman correlations between the P-CaReSS behavioral codes and validity measures

Variable	TP	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

Variable	TP	AA	SF	PR	CO	IE	VA	SA	BE	BI	AP	CR	EC	DC	NCO	NSA	NBE	LA
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-CuReSS = Parent Caring Response Scoring System; PR = Protecting; SA = Supporting/Allowing; SF = Sharing feelings; T = time-point; VA = Validating