

Parent-Child Interactions During Cancer Treatment-Related Procedures: What is Still Missing?

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INTRODUCTION

Cancer, a major public health problem in the United States (US), is the second most common cause of death in children and adolescents^[1]. Each year, approximately 12,400 children are diagnosed with cancer in the US^[2,3]. The incidence of childhood cancer has been increasing by 0.5% per year^[1]. With the development of multi-modal therapies (e.g., surgery, chemotherapy, radiation therapy and hematopoietic stem cell transplant) and supportive nursing care, the 5-year survival rate for children with cancer has increased from 58% during the mid-1970's to 83% today in the US^[2].

Children being treated for cancer require regular monitoring of disease progression, treatment effectiveness and treatment side effects. This monitoring is often completed by laboratory assays of body tissue samples that are obtained through several invasive procedures: lumbar punctures (LPs), bone marrow aspirations (BMAs), and venous access device puncture (also referred to as a "port start" when used to establish intravenous access to deliver chemotherapies and supportive care agents)^[2,4]. These invasive procedures have negative impact on children with cancer and their parents. Studies indicated that appropriate parent-child interactions can significantly benefit children's experiences about treatment-related procedures (e.g., lower pain and distress and more cooperation)^[5,6]. This editorial aimed at addressing the impact of parent-child interactions during painful procedures through the following aspects: the impact of treatment-related procedures on children with cancer, parent-child interactions and observational measures of parent-child interactions during painful procedures.

ABSTRACT

Children being treated for cancer receive a variety of treatment-related procedures, such as lumbar punctures, bone marrow aspirations and port starts. These invasive and painful procedures can negatively influence children with cancer in the short- and long-term run. Parents play important roles in physically and emotionally caring for their child during these procedures and parent-child interactions can significantly influence children's experiences during painful procedures. The purpose of this editorial was to discuss the impact of parent-child interactions during painful procedures and future research directions through the following aspects: the impact of treatment-related painful procedures in children with cancer, parent-child interactions during cancer treatment-related procedures and observational measures of parent-child interactions during painful procedures.

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Key words: Parent-child interaction; Treatment procedure; Observational measure; Childhood cancer

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IMPACT OF TREATMENT-RELATED PROCEDURES IN CHILDREN WITH CANCER

Cancer treatment-related procedures can negatively influence children with cancer and their parents. Children reported that treatment-related

procedures could be more traumatic than cancer itself^[7,8]. They experienced co-occurring symptoms related to these procedures, such as pain, fatigue and distress^[9-12]. Previous study even indicated that unrelieved pain could cause more pain-related time in bed and sleep disturbances for children with cancer^[7], which can significantly decrease children's quality of life^[13]. Additionally, memories of procedure-related pain and distress can make the anticipation of subsequent treatment-related procedures more difficult^[14] and can have negative consequences for childhood cancer survivors, such as avoidance of regular primary and long-term follow-up care^[15,16]. Moreover, experiencing their child's treatment-related procedures has been associated with the development of anxiety and post-traumatic stress symptoms in parents of children with cancer^[17].

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 starts^[3]. Nevertheless, children still express pain and distress during these invasive procedures. These painful procedures can occur in clusters within a relatively short period of time, for example, during diagnostic evaluation and treatment initiation (e.g., LPs and BMAs) and repeated at regular intervals as determined by the child's clinical condition and treatment protocol requirements (e.g., port starts). Almost all the children have to suffer procedure-related pain and distress from the combinations of these procedures. Compared with LPs and BMAs, repeated procedures (e.g., port starts) have not been amply explored as providing opportunities for improving the cancer experience for children and their parents. Thus, more research is needed to identify parent emotional and behavioral responses and parent-child interactions that contribute to child treatment responses (i.e., pain, distress and cooperation) during repeated procedures and potentially in the long-term run.

PARENT-CHILD INTERACTIONS DURING 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^[18,19]. For children being treated for cancer, parent behaviors can interactively influence child pain and distress in relation to invasive procedures. Frank and colleagues found that mother behaviors could account for 53% of the variance in child distress during immunizations^[14]. Blount et al. investigated parent-child interactions during LPs and BMAs, and found that parent coping promoting behaviors (refer 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^[5,20]. In contrast, parent distress promoting behaviors (refer 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^[5,20].

Among parent distress-promoting behaviors, reassurance and empathy have been identified as the primary parent vocalizations toward their child during invasive procedures^[21]. However, previous studies reported mixed findings for both of these verbal behaviors. Firstly, Cline and colleagues^[6] found that more parental verbalizations of empathy and reassurance were associated with less pain and

distress during port starts. Additionally, McMurtry and colleagues^[22,23] proposed that reassurance is a complex concept with sub-concepts that could cause contradictory outcomes in children undergoing immunizations. Likewise, Penner *et al*^[24] reconceptualized parent empathy comments into two categories (i.e., empathy concern and empathy distress) and found that parent empathy concern 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 interacting behaviors during invasive treatment-related procedures.

Compared with the study of parent verbal behaviors during cancer treatment-related painful procedures, parental nonverbal behaviors are rarely explored. Until now, only few studies concentrated on the impact of parent nonverbal behaviors on children's treatment responses during invasive procedures. Specifically, Peterson and colleagues developed a coding system to capture parent distance and touch toward their child during cancer procedures and found that parental interpersonal distance and supportive touch could significantly reduce children's distress and pain during invasive procedures^[25]. This result suggested that parental nonverbal behaviors should be adequately studied with verbal behaviors together so as to support parental care during invasive procedures.

It is undeniable that previous studies have provided explicit evidence regarding the importance of parent-child interacting behaviors during painful procedures. Previous studies have paid much more attention on the parent-child interactions before, during and after the procedures. However, children being treated for cancer often receive repeated procedures (e.g., port starts); the longitudinal trajectories of parent-child interactions and the influence of these behaviors on children's treatment responses (e.g., pain and distress) and later childhood outcomes (e.g., healthcare attrition and brain changes) are rarely studied. In addition, the majority of parent-child interaction studies depended on the correlational analysis rather than newer methods, such as time-window sequential analysis^[19]. Thus, a longitudinal study of parent-child interacting behaviors during repeated procedures and the influence of these behaviors on child treatment responses (i.e., pain, distress and cooperation) will fill the gap regarding how parent behaviors adjusted through the trajectories of cancer treatment as well as how these behaviors influence child treatment responses over time.

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. 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 interactions coding systems could lead to 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 interacting behaviors on child's pain, distress and cooperation during cancer treatment-related procedures. Observational measures completed by trained coders or observers are frequently used in the parent-child interaction studies^[26]. Compared with other methods (i.e., self-report and proximal-reported measures),

observational measures of parent-child interactions are more expensive and time-consuming in terms of the length of the training, data collection and coding processes^[27,28]. However, appropriate use of these observational measures can generate valuable and objective data about children, parents and healthcare providers in relation to invasive procedures^[5,6]. 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 are identified: “cure” systems that meant to conduct measurements of instrumental behaviors (i.e., task-focused) and “care” systems that meant to conduct measurements of affective behaviors (i.e., emotional-based)^[29,30]. In the context of parent-child interactions, these two systems reflect 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, which attempts to capture both types of behaviors, therefore, should be constructed in future studies.

Besides the definitive distinctions between “cure” and “care”, observational coding system 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 communications/interactions 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?)^[30]. 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.

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. Importantly, most coding systems were constructed on the basis of clinical observations or in-depth literature review rather than theory. Therefore, theory-based observational coding systems should be developed to 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.

FUTURE DIRECTIONS

On the basis of previous studies, several future directions should be further considered. Firstly, due to lack of consistency for the definitions of parent communication behaviors, studies are needed to clarify these verbal behaviors (i.e., expressions of empathy and

reassurance) within future behavioral coding measures, and then reexamine if and how parent behaviors can influence child pain, distress and cooperation during invasive procedures. Secondly, longitudinal study of parent-child interactions during repeated procedures are still needed using the new methods, such as time-window sequential analysis. These new methods will potentially provide the causal relationships among these behavioral variables. Thirdly, different observational coding systems have been used to quantify parent-child interacting behaviors during invasive procedures, which might be attributed to the mixed findings of previous studies. A systematic evaluation of these widely used parent-child interactions coding systems could potentially explain these mixed findings. Lastly, 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. In closing, more attention should be paid to the development of theory-based observational coding systems to assess parent-child interactions, the longitudinal parent behaviors adjustment during repeated painful procedures, as well as the influence of these behaviors on children’s short-term and long-term treatment responses.

CONFLICT OF INTERESTS

The Author has no conflicts of interest to declare.

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