

Parent communication and child pain and distress during painful pediatric cancer treatments

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Abstract

Children with cancer often consider treatment procedures to be more traumatic and painful than cancer itself. Previous research indicates that parents' behavior before and during painful medical procedures influences children's distress level. Understanding parents' naturally occurring communication patterns is essential to identifying families in need of an intervention to enhance coping and emotional well-being. Using the concept of definition of the situation from a symbolic interactionism theoretical framework, this study developed a typology of parent communication patterns and tested relationships between those patterns and children's responses to potentially painful treatment procedures. Analyses are based on video-recorded observations of 31 children and their primary parents (individuals functioning in a parenting role and serving as the primary familial caregivers during the observed procedure) in the USA during clinic visits for potentially painful pediatric oncology treatments. Four communication patterns emerged: normalizing, invalidating, supportive, and distancing. The most common communication patterns differed by clinic visit phase: normalizing during pre-procedure, supportive during procedure, and both distancing and supportive during post-procedure. Parents' communication also varied by procedure type. Supportive communication was most common during lumbar punctures; normalizing and distancing communication were most common during port starts. Six children (19.4%) experienced invalidation during at least one clinic visit phase. Analyses indicated that invalidated children experienced significantly more pain and distress than children whose parents used other communication patterns. This typology provides a theoretical approach to understanding previous research and offers a framework for the continuing investigation of the influence of parents' communication during potentially painful pediatric oncology procedures.

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Introduction

Annually, about 12,400 children are diagnosed with cancer in the United States (National Cancer Institute, 2005). Children with cancer often consider treatment procedures to be more traumatic and painful than cancer itself (Hedstrom, Haglund, Skolin, & von Essen, 2003; Ljungman, Gordh,

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Sorensen, & Kreuger, 1999). Although substantial progress has been made in treating childhood cancer, resulting in decreased mortality, treatment procedures remain a source of pain and distress for pediatric oncology patients. Children demonstrate fear and anxiety before, during, and after treatment procedures (Kuppenheimer & Brown, 2002). Previous research indicates that parents' communication behavior before and during invasive medical procedures affects children's level of distress (Vance & Eiser, 2004).

Parent-child interaction in this context can be viewed from a symbolic interactionism theoretical perspective. Accordingly, parents' communication "sets the stage" for children's responses by implicitly identifying roles, appropriate rules for behavior in general, and directives for coping (McCall & Simmons, 1978). Yet, what constitutes typical parent communication patterns in this context remains largely unexplored. Knowing how parents communicate during clinic visits involving potentially painful procedures could contribute to developing interventions to reduce the distress and discomfort of the children and their parents.

This study's aims were to: (1) identify prototypical parent communication patterns during painful pediatric oncology treatment visits, (2) assess the relative frequency with which parents use each type of communication pattern in general and in relation to clinic-visit phase and type of treatment, and (3) examine relationships between parent communication patterns and child responses to treatment (i.e., pain and distress). (We use the term "parent" generically to describe adults, usually family members, who accompany a child to the clinic for treatment and function in a parental role.)

Parents' communication and children's responses during painful medical procedures

Limited descriptive research exists regarding parents' real-time communication during painful pediatric oncology treatment procedures. Early research established that adults' communication behavior (including parents) preceding and during such procedures affects children's responses. Self-reported parent messages associated with reduced anticipatory distress related to chemotherapy treatments included "modeling and reassurance" in children ages 5–18 (Dolgin & Katz, 1988). Messages (from videotapes of interactions during procedures) associated with *reduced* procedural distress and

enhanced coping in children (ages 5–13) undergoing lumbar punctures and bone marrow aspirations included: adults' encouraging the child's coping behaviors (e.g., deep breathing, a relaxation technique) and use of distraction (i.e., attempts direct the child's attention away from the procedure via non-procedural talk and humor) (e.g., Blount et al., 1989; Blount, Landolf-Fritsche, Powers, & Sturges, 1991; Blount, Sturges, & Powers, 1990) and parents' bargaining and explaining the procedure (venipunctures) (Jacobsen et al., 1990).

Messages associated with *greater* child distress included parents' self-reported threats of punishment (Dolgin & Katz, 1988). Observations of clinical interactions found that adults being "overly empathic," using apologies, reassurance, and criticism; and yielding control to the child also were associated with increased child distress (e.g., Blount et al., 1989, 1990, 1991). Other observational research found parents' encouraging coping, behavioral commands, criticism, and reassurance associated with anticipatory distress (prior to the start of the procedure), and parents' behavioral commands, criticism, and reassurance associated with distress during the procedure (e.g., Dahlquist, Power, & Carlson, 1995). Further research on types of parent commands by Dahlquist et al. (2001) confirmed the association between commands and child distress during intramuscular injections (but not during lumbar punctures) for children ages 5–15 and clarified that inconsistent or vague instructions were positively associated with procedural distress while specific direct commands were negatively associated with procedural distress.

Other information on communication factors associated with pediatric patients' distress comes from intervention research. For example, engaging children in distraction (e.g., using a party blower during the procedure) reduced crying and momentary distress among some children undergoing painful treatments (e.g., Blount, Powers, Swan, & Free, 1994; Manne et al., 1990). Some promising high-tech distraction interventions involve video games, electronic "smart toys" (e.g., Dahlquist, Pendley, Landthrip, Jones, & Steuber, 2002), and virtual reality (see review by Slifer, Tucker, & Dahlquist, 2002). These interventions are all interactive and involve a continuous versus momentary distraction process, suggesting that effective distraction may require both interactivity and the ability to *sustain* distraction over a period of time. Unfortunately, no distraction research has identified a

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