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## Theory Connections

## A coping intervention for mothers of children diagnosed with cancer: Connecting theory and research

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## ABSTRACT

There are approximately 13,500 children diagnosed with cancer every year in the United States (Centers for Disease Control and Prevention, 2014). Mothers of children newly diagnosed with cancer often exhibit symptoms of stress, depression, and anxiety (Dunn et al., 2012; Fedele, Mullins, Wolfe-Christensen, & Carpentier, 2011; Felicity et al., 2009). This article describes the theoretical framework of a study which, coupled with previous research, was used to design a coping intervention to facilitate coping in mothers' of children newly diagnosed with cancer. The intervention is entitled *Creating Opportunities for Parent Empowerment- Parents of Children with Cancer* (COPE-PCC).

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Theory-based research is important in guiding nursing practice because it explains the relationships between the variables and enhances nursing knowledge and understanding of the process by which interventions are effective (Fawcett, 2005; Johnson, 1999; Reed & Shearer, 2009). Theory should act to guide nursing research by (a) aiding in identifying the problem of interest; (b) guiding the development, design, and implementation of the intervention; (c) guiding the analysis of the study; (d) explaining the findings and identifying specific links between the activities of the intervention and the outcomes; and (e) providing a framework that outlines evaluation of the effect of the intervention (Kikuchi, 2009; Sidani & Braden, 1998, 2011). The selection of the theory can be derived from the problem and population of interest.

Middle-range theories are particularly useful in research. Middle-range theories have the following characteristics: a delimited scope, a moderate number of variables, and the variables and relationships are clearly specified such that they are testable and applicable to practice (Walker & Avant, 2011).

The theoretical framework for this intervention was based on self-regulation theory (Johnson, 1999; Johnson & Leventhal, 1983) and control theory (Carver, 1979; Carver & Scheier, 1982). Both theories are based on response and adaptation to a stressful healthcare event and together may guide intervention research regarding a mother's response to their child's new cancer diagnosis. For mothers of children with cancer, the stressful healthcare event is the child's cancer diagnosis. After the mother is told that their child has cancer, they must then emotionally respond to their perceptions and feelings about their child's diagnosis. Mothers of children with cancer usually have little or no preparation for their response to their child's cancer diagnosis (Kazak et al., 2012). Self-regulation and control theory together, then, provided the framework for explaining the process through which an intervention could positively impact two main desired outcomes: 1) increased beliefs by the mother about her ability to parent their child after the cancer diagnosis and 2) decreased depression and anxiety in the mother.

## 1. Previous research

This study built on previous research supporting the Creating Opportunities for Parent Empowerment (COPE) intervention for parents of critically ill and hospitalized children, which is based on self-regulation and control theories (Melnyk, Alpert-Gillis, Hensel, Cable-Billing, & Rubenstein, 1997). The COPE program does not require a mental health provider to deliver it and has two decades of research to support its efficacy in reducing short- and long-term stress, anxiety, and posttraumatic stress disorder symptoms in parents of critically ill and hospitalized children (Melnyk et al., 2004).

There are currently three versions of COPE: 1) COPE for parents of young hospitalized children, 1 to 7 years of age, 2) COPE: PICU for parents of 2 to 7-year-old critically ill young children, and 3) COPE:

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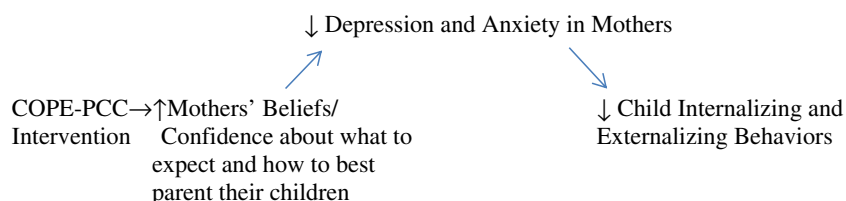


Fig. 1. Hypothesized effects of COPE-PCC on the outcomes of mothers' coping and child behaviors.

NICU for parents of low-birth-weight (LBW) premature infants. Findings from five randomized control trials (RCTs) of the different versions of COPE indicated that parents who received COPE versus those who received attention control programs reported significantly less parental stress, depression, anxiety, and fewer posttraumatic stress symptoms during as well as up to 12 months following hospitalization. Additionally, children of parents who received the COPE program had fewer internalizing and externalizing behavior problems 12 months following hospitalization than children of parents who received an attention control program. Therefore, it was plausible that COPE adapted for parents of newly diagnosed cancer children also could produce similar positive outcomes (Melnyk, Feinstein, & Fairbanks, 2006; Melnyk et al., 2004). Because of the positive findings from these studies, COPE was adapted specifically for mothers of children with cancer and called the COPE-PCC.

## 2. Theoretical framework: Connecting two middle-range theories

One approach to using theory in research is to borrow theory from one discipline and apply it to another discipline. The middle range theories that comprised the framework for this research originated in psychology but were applied from a nursing perspective and for a nursing-based purpose.

### 2.1. Self-regulation theory

Self-regulation theory proposed by Johnson and Leventhal (1983) was derived from the pioneering work of Dr. Jean Johnson, a nurse and psychologist, in which she applied a psychological theory to her studies of preparing patients for invasive healthcare procedures and surgery. Self-regulation theory was developed in a cyclic process during which propositions supported by data were retained, propositions not supported by data were altered, and new propositions were added when research produced unexpected findings. This cyclic process allowed for refinement of the theory (Johnson, 1999; Johnson & Leventhal, 1983). Self-regulation theory is a theory that explains the relationship between the concepts of healthcare experiences, coping, and health outcomes.

In self-regulation theory, the experience of stressor results in the development of a schema or perception of what changes will occur as a result of the stressful event (Johnson, 1999; Johnson & Leventhal, 1983). This cognitive schema allows the individual to develop a coping strategy that prepares the individual to deal with the actual experience. Self-regulation theory also proposes that providing individuals with concrete information about what they will see, hear, and feel during an upcoming stressful procedure or event will assist them in forming a cognitive schema that will help them to match what is occurring with what was expected. As a result of knowing what to expect, individuals can develop coping strategies to deal with it.

Melnyk (1994) extended self-regulation theory to parents of hospitalized/critically ill children by developing an intervention design to prepare parents for their children's behavioral and emotional responses to unanticipated hospitalization, which enhanced parents' cognitive beliefs about types of behaviors to expect in their children to demonstrate and how best to help their children

cope with the stressful experience. As a result, parent and child coping outcomes improved (Melnyk, 1994; Melnyk et al., 1997; Melnyk et al., 2004, 2006). In this current study, we used theory derivation (Walker & Avant, 2011) to derive from Melnyk's theoretical work a theoretical framework for developing an intervention with mothers of children who have cancer.

The intervention in this study was designed to assist mothers in developing a cognitive schema regarding what child behaviors to expect in response to a cancer diagnosis and to strengthen their beliefs about their parenting role. We theorized that once the mothers developed a positive cognitive schema roughly delineating the potential responses that they and their child might demonstrate following a new cancer diagnosis, and through the behavior-skills portion of the intervention information, the mothers would be able to develop strategies to cope with anticipated emotional and behavioral responses. As a result, it was anticipated that the mothers of children newly diagnosed with cancer who received this information would demonstrate enhanced coping skills and report fewer depressive and anxiety symptoms.

Psychosocial interventions driven by self-regulation theory often include preparatory or anticipatory information (Melnyk et al., 2004). In this case, the information included typical changes to be expected in the diagnosed children's emotions and behaviors. Utilizing self-regulation theory which supports the use of concrete information to prepare for an event before it occurs, this intervention included medical play in which the mother and child engaged in role playing for an upcoming event (i.e., medical procedure) to promote positive rehearsal in preparation for the emotional and behavioral responses of the child to the actual event. This information was developed based upon the research literature that outlined the potential responses of children after their cancer diagnosis (Harper et al., 2013; Melnyk et al., 2004; Norberg, Poder, & von Essen, 2011). According to self-regulation theory, concrete and objective anticipatory information offered to mothers of the affected children will strengthen the mothers' awareness, understanding, and interpretation of the child responses and provide them with concrete suggestions of parenting behaviors that should facilitate their child's coping.

The ultimate goal of using self-regulation theory in the theoretical framework for this intervention is to assist the mothers in forming a cognitive schema/stronger beliefs about the typical emotions and behaviors to expect in themselves and their children, which should result in improved maternal coping outcomes (for example, fewer anxiety and depressive symptoms). In addition, since emotion is contagious according to the emotional contagion hypothesis (VanderVeer, 1949), the children of mothers who receive the coping intervention are expected to have fewer externalizing and internalizing behaviors.

### 2.2. Control theory

Control theory postulates that a discrepancy between a current state (for example, parenting a child newly diagnosed with cancer) and a pre-existing standard or goal state (parenting a healthy child) should motivate behaviors to help an individual to once again reach their standard or goal (Carver, 1979; Carver & Scheier, 1982). However, in stressful or unfamiliar situations, there are often barriers such as uncertainty, stress, and lack of knowledge that block the ability to engage in behaviors to reach a goal. Anxiety, environmental constraints,

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