



Nursing theory as a guide into uncharted waters: Research with parents of children undergoing cancer treatment



Jouhayna Bajjani-Gebara, PhD, PMHNP-BC^{a,*}, Pamela G. Reed, PhD, FAAN^{b,1}

^a University of Maryland, University Health Center

^b University of Arizona, College of Nursing

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ABSTRACT

Being a parental caregiver for a child who is undergoing cancer treatment profoundly impacts significant numbers of parental caregivers and their well-being. This article focuses on the use of theory, philosophy, and empirical knowledge in guiding research designed to both describe and explain influences on well-being of parental caregivers of children undergoing cancer treatment. Other aspects of the research are discussed as well, including practice-relevant findings. Findings indicated the co-existence of both positive and negative well-being and that each has unique predictors. Self-transcendence mediated the relationship between resilience and well-being in parental caregivers. Clinical implications for these findings are also presented.

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Being a parental caregiver for a child who is undergoing cancer treatment profoundly impacts significant numbers of parental caregivers and their well-being. Despite advances in cancer treatment, each year 160,000 parents learn that their child has cancer and 90,000 parents lose their child to cancer (World Health Organization & International Union Against Cancer, 2005). Childhood cancer continues to be the leading cause of death from disease in children under fifteen (National Cancer Institute, 2008). There is extensive empirical evidence that parental caregivers of these children suffer negative well-being including: depression, anxiety, posttraumatic stress, increased illness, decreased quality of life, strained marital relationships, and early death (da Silva, Jacob, & Nascimento, 2011; Fotiadou, Barlow, Powell, & Langton, 2008; Klassen et al., 2008; Rivera, 2008; Witt et al., 2010). The negative consequences on the well-being of parental caregivers strain their participation in their ill child's complex healthcare needs (Melnyk et al., 2004) and even affect the child's own well-being. Most research on well-being of parental caregivers of children who have cancer has focused mostly on children in the survivorship stage and not in cancer treatment (Barakat, Alderfer, & Kazak, 2006; Michel, Taylor, Absolom, & Eiser, 2009). Thus, more research is needed and particularly explanatory research that can improve understanding of the predictors and underlying mechanisms involved in parental well-being when their children are undergoing cancer treatment.

Obtaining an understanding of parental caregivers' well-being, in terms of what factors predict well-being and by what mechanisms, should precede any expenditure of resources on intervention research aimed at enhancing well-being. Acquiring knowledge of what works and why it works reduces the research-to-practice gap (Sidani & Braden, 1998) and constitutes the judicious use of resources. Thus, the first author of this article planned and implemented this study to investigate the well-being of parental caregivers of children undergoing cancer treatment, and is the referent of first-person terms in this article. The second author was an advisor on the project and co-writer of this article. This article highlights the use of theory as well as other knowledge in guiding new research into potential mechanisms underlying the well-being of parental caregivers of children undergoing cancer treatment. Research findings relevant to practice are also briefly presented.

1. Aims of the study

The first step in the research was to establish the aims based on a search of the literature to learn about what other studies had been done and what theories were used in the research. A thorough review of the literature revealed three major areas relating to parental well-being as lacking research, and these areas became the three aims of this study:

- 1) To identify positive (general well-being) and negative (depression and anxiety) aspects of parental well-being;
- 2) To describe parental personal factors and/or child-based contextual factors that predict parental positive and/or negative well-being;

* Corresponding author. Tel.: +1 301 314 8106.

E-mail addresses: jbajjani@email.arizona.edu (J. Bajjani-Gebara),

preed@email.arizona.edu (P.G. Reed).

¹ Tel.: +1 520 626 4131.

- 3) To determine the underlying mechanism through which parental personal factors, such as resilience, facilitate positive and negative well-being

2. Formulating the theoretical framework: behind the scenes

2.1. Philosophical views

During the literature review, in preparation for formulating the theoretical framework, I clarified our own philosophical views as these shape one's choice of guiding theories for research, and influence research and practice overall. I subscribed to two philosophical views in particular: Fawcett's (1993) *Simultaneous Action* worldview and Reed's (2011) *intermodernism*.

The **Simultaneous Action (SA)** worldview regards humans as wholes, more than the sum of their parts and who are in rhythmical and mutual changes with their environments in self-organizing ways (Fawcett, 1993). The changes that humans go through involve periods of organization, disorganization, and more complex organization (Buck, 2006; Fawcett, 1993; Reed, 1992, 1997; Richardson, 2002). Consistent with the SA worldview, was the view that parental caregivers are inherently capable of self-organizing in order to meaningfully integrate challenges in a manner that sustains their well-being despite the adversity of their child's cancer. I regarded nursing as having an important role in facilitating humans' self-organization and well-being promotion (Fawcett, 1993). Hence, the current study investigated both positive and negative aspects of well-being outcomes, well-being predictors, and mediators that promote positive well-being in parents as opposed to solely focusing on how their well-being deteriorates given their children's cancer.

I was also aligned with Reed's (2011) **intermodernism**, a philosophical perspective that values diversity in forms of empirical evidence, champions the search for meaning and personal knowledge in nursing, and embraces multiple paths including the pragmatic in the quest for nursing knowledge. Intermodernism sits at the intersection of modernism and postmodernism and offers an extension of knowledge development by clinicians educated to use various patterns of knowing in practice (Reed, 1995, 2006).

2.2. Guiding mid-range theories

In the quest to find theories that could guide the understanding of well-being in parents of children with cancer, I was particularly influenced by two theories: *The Resiliency Model of Family Stress, Adjustment, and Adaptation* (McCubbin & McCubbin, 1993, 1996) and *The Theory of Self-Transcendence* (Reed, 1991b, 1992, 2013). The Resiliency Model of Family Stress, Adjustment, and Adaptation purports that families with high resilience factors, such as hardiness, have an easier time adjusting if they view changes as growth producing, develop a sense of control over their outcomes in life, and use an active rather than passive orientation in adapting to the cancer situation. Although this theory is applicable to the study of well-being in parents of children with cancer, it does not explicate the underlying mediator through which resilience facilitates well-being and also underestimates the role of spirituality as a driving force in the process of familial reintegration from life's adversity. This theory mentions spirituality in the context of it being a desired outcome within the concepts of 'balance and harmony' (McCubbin, Balling, Possin, Frierdich, & Bryne, 2002; McCubbin & McCubbin, 1993, 1996), which did not fit with my view of humans as wholes whose spirituality is indivisible from their inherent processes of self-organization.

The Theory of Self-Transcendence was especially suited to guide our current study because it was consistent with our SA worldview and was particularly relevant in the context of parents of children with cancer. Similar to the SA worldview's depiction of humans as indivisible wholes (Fawcett, 1993), the theory of self-transcendence describes self-transcendence as including the following indivisible human

dimensions: cognitive, emotional, behavioral, and spiritual (Reed, 2009). This theory was particularly relevant in the context of childhood cancer because self-transcendence specifically becomes evident in situations that confront the individual with personal mortality or that of a loved one (Reed, 2009), as in the context of being the parent of a child with cancer. Also this theory provided an explanation of how self-transcendence enables individuals to sustain well-being through expanding their self-boundaries in four directions: a) intrapersonally (inwards); b) interpersonally (outwards); c) transpersonally (upwards); and, d) temporally (by linking one's past and future to make meaning of the present) (Reed, 1991b, 2013). Resilience may be generated from the vulnerability a parent experiences when their child must undergo cancer treatment. Well-being is a complex phenomenon, with positive and negative aspects that may co-exist simultaneously in a person.

2.3. Theoretical framework and testing relationships between variables

Both theories helped frame my theoretical framework. The framework posited that parental factors (resilience and possible demographic variables) and child-based contextual factors (cancer characteristics and possible demographic variables) were positively related to parental well-being. The framework also proposed that self-transcendence mediated the relationship between parental resilience and well-being. The study was designed to test these propositions, and also to describe parental and child-based characteristics that may be relevant to explaining parental well-being in the context of child cancer treatment. The current study also investigated the co-existence of negative and positive well-being.

Theory was linked to research aims as follows: *Parental well-being* was the main concept of interest consisting of both positive and negative aspects that coexist (Aim 1). Both *parental personal factors* as well as *child-based contextual factors* link directly to *parental well-being* and were hypothesized to predict parental well-being (Aim 2). *Parental resilience* was hypothesized to link to *parental well-being* through the underlying generative mechanism of *parental self-transcendence*, which was the hypothesized mediator for the relationship between *parental resilience* and *parental well-being* (Aim 3).

3. Patterns of knowing and theory in generating research hypotheses

According to Hildegard Peplau's *cycle of inquiry* (see Reed, 1996), practice has an important role in formulating theory for research. I anchored theoretical ideas in my interpersonal therapeutic relationships with clients and their families, as well as in personal, empirical, and conceptual patterns of knowing (Carper, 1978; Fawcett, Watson, Neuman, Walker, & Fitzpatrick, 2001; Schultz & Meleis, 1998). The personal pattern encompasses knowledge about being authentic with others, which is at the core of the nurse–patient relationship. The empirical pattern of knowing includes facts obtained through empirical research. The conceptual pattern of knowing includes theories that are generated to explain patterns of client experiences across situations or nursing phenomena. These patterns of knowledge fueled my abductive 'leap in thinking' to propose explanations (as *hypotheses*) about parental well-being, its predictors, and mediators.

Based on the **personal pattern of knowing**, I hypothesized that *positive well-being and negative well-being coexist in parents of children with cancer* (Hypothesis 1). Throughout my work as a consultation–liaison psychiatric nurse dealing with parents of children with cancer, I learned that parents who seemed to do better were those who were able to generally put things into perspective beyond the concrete aspect of the here and now. They were able to shift their focus to things that connected them with pleasant entities, such as spiritual practices, and family and friend gatherings. Parents also fostered a self-connectedness by trying to be as healthy as they could be despite spending extended amounts

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