



Refinement of an Instrument to Measure the Needs of Parents of Sick Children in the Context of Family Centered Care

Veronica Feeg, PhD, RN, FAAN^{a,*}, I-Chan Huang, PhD^b, Jennifer E. Mannino, PhD, RN^c,
Deborah Miller, MSN, RN, CNS, CNN^d, Cecilia Hau-Yee Kuan, PhD, RN^e

^a Center for Nursing Research and Evaluation, Barbara H. Hagan School of Nursing, Molloy College, 1000 Hempstead Avenue, Rockville Centre, New York 11571, United States of America

^b Department of Epidemiology and Cancer Control, St. Jude Children's Research Hospital, 262 Danny Thomas Place, MS#735, Memphis, TN, United States of America

^c Barbara H. Hagan School of Nursing, Molloy College, 1000 Hempstead Avenue, Rockville Centre, NY 11571, United States of America

^d Retired Clinical Specialist, Fairfax, VA, United States of America

^e School of Nursing, St. Teresa's Hospital, 20 Lomond Road, Kowloon, Hong Kong

ARTICLE INFO

Article history:

Received 2 May 2018

Revised 21 August 2018

Accepted 26 August 2018

Available online xxxx

Keywords:

Parenting

Seriously ill children

Instrument development

ABSTRACT

Background and Purpose: The purpose of this study was to refine an instrument to capture the perceived needs of parents whose children are seriously ill. This article describes the psychometric properties of the Parents' Needs Scale (PNS), a translated, revised 22-item short form from an original instrument that was developed and tested on parents of children with cancer in Hong Kong.

Methods: The study was done in three stages that included (a) factor analysis of two samples recruited from clinics in Northern Virginia of parents of children with cancer ($n = 74$) and end stage renal disease (ESRD) ($n = 30$); (b) known groups validity testing with two groups of parents recruited in a parallel study on children with special needs ($n = 15$) and a control group of well children ($n = 23$); and (c) concurrent validity testing on the subsample of parents of children with special needs using the known measure of Impact on the Family Scale (IFS). Data collection for the stages included mailed questionnaires and follow-up telephone interviews.

Results: Exploratory factor analysis using the common factor approach identified two domains: (1) needs related to my child's illness and (2) needs unrelated to my child's illness. The factorial structure was followed by item scaling tests to determine item-level convergence and discriminative validity, as well as scale reliability for the two domains (Cronbach's alpha = 0.93 and 0.90). Domain-level discriminant validity tests yielded significant differences on several expected characteristics of the child and/or family based on the literature. The final 22-item scale was reworded and used to establish known groups validity by comparing the two groups of children with acute illnesses from the previous study with two control groups of parents of children who were well or children with special needs but not acutely ill, yielding significant results on both factors ($p < 0.001$). A final test of concurrent validity was performed on the parents of children with special needs measures of parent need with their reported impact on the family yielding significant correlations on predicted variables.

Conclusions: The PNS can measure parents' needs with demonstrated psychometric validity and reliability.

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Family-centered care is an approach to care that is grounded in beneficial partnerships between families and healthcare professionals to recognize the importance of the family in the patient's life (American Academy of Pediatrics Committee on Hospital Care and Institute for Patient- and Family-Centered Care, 2012). Family-centered care is defined as a collaborative relationship between families and professionals in the pursuit of being responsive to the priorities and needs of families wherever they seek healthcare (Coker, Rodriguez, & Flores, 2010, p. 1160). That importance goes beyond separate recognition of

provider-parent relationships in the care of the child, but one that recognizes the parents' central connection to their child in a healthcare system relationship toward a mutual therapeutic benefit to child and parent. Mutuality not only embodies the philosophy of family-centered care; it acknowledges and supports the evolution of parents and nurses toward greater competency in their respective roles. Curley (1997) defined mutuality as a synchronous, co-constituting relationship, one where pediatric nurses seek synergistic, respectful relationships with parents that are responsive to parents' individual needs. They create opportunities for parents to assume a level of engagement that they choose and provide parents with the knowledge, skills, and support they need to better understand and manage their child's healthcare situation (Curley, Hunsberger, & Harris, 2013).

* Corresponding author.

E-mail addresses: vfeeg@molloy.edu (V. Feeg), i-chan.huang@stjude.org (I.-C. Huang), jmannino@molloy.edu (J.E. Mannino).

Over the past four decades, researchers have described and measured the needs, adaptive tasks, coping methods and psychosocial impact on parents whose children are hospitalized or are living with chronic, serious, and/or critical illnesses (Callery, 1997; McCubbin et al., 1983; McCubbin & Patterson, 1983; Reichman, Corman, & Noonan, 2008; Shields, Hunter, & Hall, 2004). Numerous stressors are imposed on families when a child is seriously ill. Parents are stressed by demands to perform daily medical tasks including treatments and medications, keep doctor appointments, obtain laboratory and medical tests, and care for children during periodic hospitalizations (Curley & Wallace, 1992; Hoekstra-Weebers, Jaspers, Kamps, & Klip, 2001; Shields, Young, & McCann, 2008), in particular when they are in the pediatric intensive care unit (PICU) (Miles & Carter, 1982). The burden of these tasks on parenting can result in unnecessary and unmitigated stress on relationships within the family and work life, in addition to serious financial and emotional challenges that are inevitable consequences of child illness (Callery, 1997; Quittner et al., 1998; Smith, Swallow, & Coyne, 2015).

Implementation of Family Centered Care (FCC) is a goal that guides providers to provide care for the child and parents together, which requires an understanding of the parents' needs as well as the child's in order to offer be effective. FCC has been adopted as a philosophy of care for pediatric nursing (Lewandowski & Tesler, 2003), and it requires a collaborative relationship between families and professionals with the goal of being responsive to the priorities and needs of families (Curley et al., 2013). In Family Centered Care (FCC), it is as important to understand the needs of parents who are partners in their child's care as it is to understand the needs of the child. Many researchers have used qualitative approaches to understand parents' needs (Foster, Whitehead, Maybee, & Cullens, 2013). Several researchers have undertaken studies to operationalize and measure parents' needs, describing various tools available to researchers with validity and reliability such as the needs of parents questionnaire (NPQ) (Bragadottir, 1998; Shields et al., 2004), which has been used in multiple studies (Foster, Whitehead, & Maybee, 2016) and in several countries (Ferreira, Melo, Reis, & Mello, 2010; Foster, Whitehead, & Maybee, 2010; Shields et al., 2008; Soderback & Christensson, 2008). These are useful for research but methodologically cumbersome and unique to particular clinical practice settings. A practical and easy tool that can be implemented in numerous settings is needed.

The purpose of this study was to modify and refine an existing instrument that measures parents' needs into a psychometrically valid and reliable tool that is clinically relevant for multiple populations of parents with sick children. The source 69-item questionnaire was developed in Hong Kong to identify categories of needs over time of parents whose children had cancer with varying diagnoses and severity of illnesses (Kuan, 2000). In that study, the researcher developed an English translation and back-translation capturing the "importance" of parents' needs identified in an extensive mixed-methods study.

The researchers in this study modified the English translation of the Hong Kong study. The translated version was edited for readability to assess the "importance" of the needs components of the questionnaire and to build a conceptually sound instrument that can capture and measure parents' "needs" in the United States. This version was then subjected to psychometric analysis conducted in three stages using three overlapping samples: (1) a factor analysis to confirm the reduction of items and construct validity (known groups) on two groups of sick children (cancer and ESRD); (2) a test for known groups validity on the sick children data (combining cancer and ESRD) with a control sample of non-sick children (combining special needs children and well children) for comparison; and (3) a test for concurrent validity with two different measures on a sub-sample of one of the previous groups (special needs children). The rationale for this scale reduction and reassessment was based on the difficulties in administering previously developed scales for research purposes. This new scaled measure may be feasible for use in clinical practice and serve as a measure in intervention studies

that attempt to meet the needs of parents over the course of a child's illness.

Background and Conceptual Framework

The literature abounds with studies on parenting in general and parenting a sick child specifically. While mothers assume most of the burden of care related to the child's illness (Bristol, Gallagher, & Schopler, 1988; Green, 2007) father involvement appears to influence marital satisfaction and family functioning (Gavin & Wysocki, 2006) and impact on the parents' responses to a child's illness (Stein & Jessop, 2003). Parent characteristics such as psychological stress and child characteristics such as severity of illness mutually contribute to the psychosocial needs of parents (Hoekstra-Weebers et al., 2001; Miles, Burchinal, Holditch-Davis, Brunssen, & Wilson, 2002; Whiting, 2014). Research suggests that social support to buffer the effects of chronic stress result in better family adaptation to child illness and fewer psychological symptoms (Cohen, Gottlieb, & Underwood, 2000). Financial demands are also important in understanding the needs of parents when their child is hospitalized or seriously ill (Callery, 1997; McGrath, 2001; Shields & King, 2001). An integrative and multi-conceptual approach is necessary in understanding parents' needs and how to meet those needs. This is a critical foundation of the FCC model of care in hospitalized children.

A variety of conceptual models have shaped the development of research on parents' responses to their children's illness. These models offer various approaches to describe parenting and adaptation to the child's condition when based on these models. These can be categorized as (a) social-ecological models such as Wallander et al. (1989); (b) family coping and adaptation to stress and resiliency models such as McCubbin and McCubbin (1991); (c) psychological patterns of family stress and functioning (Abidin, 1990); (d) caregiving demands (James et al., 2002); or (e) parent satisfaction models (Shields, Kristensson-Hallstrom, & O'Callaghan, 2003). Parents' needs have been researched in conjunction with adjustment to hospitalizations and in relation to the health services received while their children have undergone treatment or living with disability or illness (Ireys & Perry, 1999; Wallander, Varni, Babani, Banis, & Wilcox, 1989). This has been particularly notable with the advent of FCC service models based on close and continuous involvement of the child's family (Ahmann & Johnson, 2001; Shields et al., 2003).

Ireys and Perry (1999) developed and evaluated the Multidimensional Assessment of Parental Satisfaction for Children with Special Needs (MAPS/CSN) in two studies based on 158 parents with 4 selected chronic conditions and 302 parents of children with diverse chronic conditions. The tool focused on parents' responses to the items related to providers' efforts such as "managing child's chronic illness," "really listening to your opinion," "ability to answer questions about condition," and "amount of information and guidance." The standardized items were factor analyzed yielding a 12-item unidimensional instrument measuring the health care provider identified needs rather than a parents' perception that the items represent their own needs. Shields et al. (2004) developed a tool that measured 85 parents' reported needs in a hospitalized setting that tested 55 items that were collapsed into 6 categories: (1) need to trust; (2) need to be trusted; (3) need for information; (4) need for support; (5) need for human and physical resources; and (6) needs relating to the ill child and other family members.

In children with cancer, James et al. (2002) reported that little is known about parents' perception of what helps or hinders them with their caregiving responsibilities. In their descriptive exploratory study, 151 parents responded to six open-ended questions that were part of the "Care of My Child with Cancer" instrument. Based on content analysis, the most frequently reported effect on parental caregiving involved the negative physical and emotional health of the parent. The most desired forms of assistance with their roles were periodic relief from direct

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