

## Parental Bereavement Needs in the Pediatric Intensive Care Unit: Review of Available Measures

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### Abstract

**Background:** Pediatric intensive care units (PICUs) are highly technological settings in which advanced care is used to restore health to critically ill children; however, they are also places where children die. Understanding the needs of parents bereaved in this setting is essential for better family care.

**Objective:** To systematically review the extant literature to identify instruments potentially useful for assessing the needs of parents bereaved in the PICU.

**Methods:** We searched PubMed<sup>TM</sup>, CINAHL<sup>TM</sup>, and Health and Psychosocial Instruments<sup>TM</sup> for tools to assess family needs during a relative's hospitalization. From 357 abstracts, 96 articles were reviewed that described 31 instruments. Fifteen instruments were selected based on their (1) use with parents and/or the bereaved, (2) use in PICU, neonatal intensive care, or pediatric wards, (3) measurement of family needs or related constructs, and (4) published psychometrics. Need-related constructs included satisfaction with family care and environmental stress since these have been related to met and unmet needs, respectively.

**Results:** No instruments specifically designed to assess the needs of parents bereaved in the PICU were identified. Most tools reviewed showed validity and reliability in the populations and settings for which the tools were intended; however, validity and reliability were not established for parents bereaved in the PICU. No tools addressed the full range of needs for parents bereaved in the PICU.

**Conclusions:** A new instrument is needed to adequately assess the needs of parents bereaved in the PICU. Patient conditions, illness trajectories, and life course perspectives must be considered in designing a new tool.

### Introduction

THE PEDIATRIC INTENSIVE CARE UNIT (PICU) is a special context for child death and parental bereavement. PICUs are highly technological, faced-paced settings in which advanced care is used to restore health to critically ill children. However, PICUs are also places where children die. Approximately 53,000 infants and children die annually in the United States.<sup>1</sup> Over 50% of these deaths occur in hospitals; 80% following intensive care.<sup>2,3</sup> In the PICU, approximately 60% of deaths occur after a decision has been made to limit or withdraw treatment.<sup>4</sup> Some parental needs described in this setting include unrestricted visiting, honest communication, and shared decision-making.<sup>5-9</sup> Understanding parental needs in the PICU is essential for better family care.

According to the classic definition by Parkes and Weiss,<sup>10</sup> bereavement encompasses the entire experience of antici-

pating a death, the death itself, and the subsequent adjustment to living. The term need commonly refers to a lack of something requisite, desirable or useful, or a physiologic or psychosocial requirement for a person's wellbeing.<sup>11</sup> Prior single-site qualitative research using these definitions described parents' perspectives on their needs near the time of their child's death in the PICU and showed how parents' needs are shaped by complex interactions between individual, familial, and organizational cultures and by the ways in which care is both provided and received.<sup>12-14</sup> However, to generalize parents' bereavement needs across PICU settings, parents' needs must be assessed in multi-center research using well-designed tools suitable for bereaved parents.

We conducted a systematic literature review to identify instruments potentially useful for measuring the needs of parents bereaved in the PICU. Based on this review, we

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describe tools considered, discuss tool performance, and provide rationale for development of a new tool.

## Methods

### Literature search

We searched PubMed<sup>TM</sup>, CINAHL<sup>TM</sup>, and Health and Psychosocial Instruments<sup>TM</sup> using the following search terms and key words in various combinations:

1. Needs assessment or health services needs and demands or human needs or needs or patient satisfaction or satisfaction.
2. Critical care or intensive care (which includes pediatrics) or intensive care, neonatal.
3. Family or nuclear family.
4. Questionnaires or scales or research instruments or measures.
5. Bereavement or grief or death or terminal care or hospice care.

The search was limited to publications in English. No restrictions were placed on subject age or year of publication. A total of 357 unique abstracts were identified.

### Abstract screening process

One author (K.L.M.) screened abstracts using three criteria: (1) the abstract included an instrument, (2) used to measure needs or experiences, and (3) used with family members during or after a relative's hospitalization. Review articles were also examined for articles meeting screening criteria. Ninety-six abstracts were selected; full articles were reviewed by team members to confirm screening criteria were met. Since many papers included the same instrument, we sorted papers by tool for comparison. Thirty-one instruments were identified.

### Instrument selection process

Instruments were reviewed by two authors (K.L.M. and S.M.S.) and selected if at least one article reported: (1) use with parents and/or the bereaved, (2) use in PICU or related hospital settings, (3) measurement of family needs or related constructs, and (4) psychometrics. Related hospital settings included neonatal intensive care units (NICUs) and pediatric wards. Need-related constructs included satisfaction with family care and environmental stress since these have been related to met and unmet needs, respectively. Instruments were excluded that primarily measured family perceptions of patients' needs.

## Results

Fifteen instruments met selection criteria. None were designed to assess the needs of parents bereaved in the PICU. However, tools were identified to assess PICU and NICU parent needs generally (Table 1), PICU and NICU parents and need-related constructs (Table 2), parent needs on pediatric wards (Table 3), and bereaved parents and need-related constructs (Table 4).

### PICU and NICU parent needs

The Critical Care Family Needs Inventory (CCFNI) is the most widely used instrument to assess family needs in adult, pediatric, and neonatal intensive care.<sup>15-43</sup> Based on crisis theory, the

original CCFNI includes 45 need statements developed through literature review and a survey of graduate student nurses.<sup>15</sup> Respondents rate the importance of each need on a four-point scale from "not important" to "very important" and describe whether the need was met and by whom (doctor, nurse, etc.). Construct validity of the CCFNI was first assessed by factor analysis of a large pooled data set<sup>23</sup> that yielded five dimensions including assurance, information, proximity, support, and comfort.

Studies using the CCFNI have shown assurance, information and proximity are most important to relatives of critically ill adults.<sup>28,33,34,36,37,39,40</sup> Families identify nurses as more likely to provide assurance and doctors as more likely to provide information.<sup>15,30,39</sup> Studies comparing families' and staff's perceptions of family needs show that staff underestimate family needs and prioritize needs differently.<sup>18,20,22,30,33,34,37</sup> Several studies using the CCFNI include parents of critically ill patients, however, direct comparisons of parents' needs versus those of other relatives are rare.<sup>58</sup> Most studies exclude bereaved family members. The CCFNI was modified for use in PICUs and NICUs.<sup>21,25,26,32,35</sup> Using modified versions, parents also rank assurance and information needs highest. The need "to be recognized as important to my ill child's recovery" has been rated highly by parents suggesting that maintaining parental role is an important aspect of parental coping with critical illness.<sup>21,32</sup>

The 45-item Needs Met Inventory (NMI) was designed to coincide with the CCFNI.<sup>44-50</sup> Respondents report the frequency that each need was met on a four-point scale from "never met" to "always met." The NMI has been used with the CCFNI and as a stand-alone instrument. Most papers identified in our review did not address psychometrics of either the NMI alone or the CCFNI/NMI combination. Recently, the NMI was used in a pilot study assessing PICU parents' needs during the first 24-36 hours after admission.<sup>50</sup> Assurance needs were met most often and support needs least often. Parents bereaved in the PICU were not included.

The Society of Critical Care Medicine (SCCM) Family Needs Assessment (SCCMFNA) is a 14-item instrument based on the CCFNI that has been modified to assess family needs and satisfaction with intensive care.<sup>51-55</sup> Respondents report the frequency that each need is met on a 4-point scale from "almost all the time" to "none of the time." Factor analysis yielded 4 domains including provider attitude, communication, comfort skills and family isolation.<sup>51</sup> SCCMFNA study findings indicate that families perceive provision of information and continuity of care as the least met needs during ICU admission.<sup>51,52,54,55</sup>

An investigator-developed unnamed instrument was used to assess needs, responses, and satisfaction of mothers in three NICUs in different regions of Thailand.<sup>56</sup> The tool consists of 75 items addressing 5 need domains including personal, psychological, information, maternal role, and treatment and nursing care. Each item is rated from 0 (no need/no response/no satisfaction) to 3 (highest need/highest response/highest satisfaction). Mothers' scores differed between regions. Findings support staff's need to consider the background, culture, and geographic location of parents, and individual and unit differences in need expression.

### PICU and NICU parents and need-related constructs

Several instruments warrant review because they were developed or tested in PICUs or NICUs and measure

TABLE 1. MAJOR TOOLS AND RELATED ARTICLES USED TO ASSESS PICU AND NICU PARENT NEEDS

Author, year	Country	No. of subjects <sup>a</sup>	Parents no. (%) <sup>b</sup>	Bereaved no. (%) <sup>c</sup>	Patients	Setting	Items (no.)	Constructs measured	Reliability and validity
Molter, 1979	USA	40	1 (3%)	-	Adult	ICU	45	Importance of needs; needs met (y/n); met by whom	Content validity—experts
Bouman, 1984	USA	34	3 (9%)	-	Adult	ICU	15	Importance of needs	Content validity—Q sort to identify 15 most important items
Leske, 1986	USA	55	23 (42%)	-	Adult	ICU	45	Importance of needs	Content validity—experts ICR $\alpha = 0.98$
Norris et al., 1986	USA	40 (20 relatives, 20 nurses)	—	-	Adult	ICU	30	Importance of needs	Content validity—Q sort to identify 30 most important items; ICR $\alpha = 0.85$
Spart et al., 1986	USA	25	4 (16%)	-	Adult	ICU	45	Importance of needs	ICR $\alpha = 0.88$
Forrester et al., 1990	USA	141 (92 relatives, 49 nurses)	32 (35%)	-	Adult	Surgical & Neurol. ICU	30	Importance of needs	ICR $\alpha = 0.94$
Kirschbaum, 1990	USA	41	41 (100%)	-	Pediatric	PICU	53	Importance of needs	Content validity—experts
Jacono et al., 1990	Canada	79 (49 relatives, 30 nurses)	+ (% ND)	-	Infants and adults	NICU and ICU	30	Importance of needs	-
Leske, 1991	USA	677	156 (23%)	-	Adult (87%) Pediatric (13%)	ICU	45	Importance of needs	Factor analysis yields 5 domains; Interitem correlations 0.3–0.55; Item—total correlations 0.15–0.6; ICR $\alpha = 0.92$ for total scale; ICR $\alpha = 0.61$ –0.88 for the 5 domains
Rukholm et al., 1992	Canada	95	-	-	Adult	Cardiac ICU	47	Importance of needs	Split half reliability 0.92 (Spearman-Brown), 0.93 (Guttman); ICR $\alpha = 0.93$
Farrell et al., 1992	England	27	27 (100%)	-	Pediatric	Cardiac PICU	32	Importance of needs	Content validity—experts
Fisher, 1994	USA	30	30 (100%)	-	Pediatric	PICU	59	Importance of needs	Content validity—experts; ICR $\alpha = 0.89$
Daly et al., 1994	USA	60	-	-	Adult	Surgical ICU	45	Importance of needs; needs met (y/n)	-
Blackmore, 1996	England	14	1 (7%)	-	Adult	Cardiac ICU	45	Importance of needs; needs met (y/n); met by whom	Content validity—experts
Quinn et al., 1996 (Parts 1 & 2)	Ireland	606 (255 relatives, 351 nurses)	+ (% ND)	-	Adult	ICU	30	Importance of needs; needs met (satisfaction); met by whom	-

(continued)

TABLE 1. (CONTINUED)

Author, year	Country	No. of subjects <sup>a</sup>	Parents no. (%) <sup>b</sup>	Bereaved no. (%) <sup>c</sup>	Patients	Setting	Items (no.)	Constructs measured	Reliability and validity
Zarpe et al., 1997	Spain	85	8 (9%)	-	Adult	ICU	34	Identified needs; needs met	-
Scott, 1998	USA	38 (21 parents, 17 nurses)	21 (100%)	-	Pediatric	PICU	53	Importance of needs (satisfaction)	ICR $\alpha = 0.94$ (parents) ICR $\alpha = 0.93$ (nurses)
Tin et al., 1999	Hong Kong	88 (52 relatives, 36 nurses)	4 (8%)	-	Adult	Neuro-surgical ICU	45	Importance of needs; needs met (y/n); met by whom	Chinese version; Test-retest reliability 0.8622 (family), 0.7983 (nurses)
Leung et al., 2000	Hong Kong	82 (37 relatives, 45 nurses)	-	-	Adult	ICU	45	Importance of needs	Chinese version; ICR $\alpha = 0.84$ for total scale; ICR $\alpha = 0.65-0.82$ for the 5 domains
Ward, 2001	USA	52	52 (100%)	-	Infants	NICU	56	Importance of needs	Content validity—experts; ICR $\alpha = 0.91$
Bijttebier et al., 2000, 2001	Belgium	381 (200 relatives, 181 ICU staff)	37 (19%)	-	Adult (% ND) Pediatric (%ND)	ICU	45	Importance of needs	Dutch version; Factor analysis yields 5 domains; ICR $\alpha = 0.62-0.80$ for the 5 domains
Delva et al., 2002	Belgium	200	37 (19%)	-	Adult (% ND) Pediatric (%ND)	ICU	45	Importance of needs	Dutch version; Same data as Bijttebier et al., 2000; same validity and reliability reported
Lee et al., 2003	Hong Kong	40	-	-	Adult	ICU	45	Importance of needs; needs met (y/n); met by whom	-
Redley et al., 2003, 2004	Australia	61	8 (13%)	6 (10%)	Adult	ED	40	Importance of needs; needs met (satisfaction)	Content validity—experts; interrater reliability for suitability of items = 0.9; ICR $\alpha = 0.9$
Chien et al., 2005	Hong Kong	290	55 (19%)	-	Adult	ICU	45	Importance of needs	Chinese version; Content validity—experts; Factor analysis yields 5 domains; Contrasted groups; Correlations with other scales; ICR $\alpha = 0.9$ for total scale; ICR $\alpha = 0.8-0.92$ for the 5 domains
Freitas et al., 2007	Brazil	91	-	-	Adult	ICU	43	Importance of needs; needs met (satisfaction)	Portuguese version; ICR $\alpha = 0.79$ for total scale; $\alpha = 0.27-0.62$ for the 5 domains; Satisfaction scale ICR $\alpha = 0.86$ for total scale
Warren, 1993	USA	94	+ (% ND)	-	Adult	ICU & cardiac ICU	45	Importance of needs; needs met (frequency)	-
Mendonca et al., 1998	USA	52	6 (12%)	-	Adult	ICU	45	Importance of needs; needs met (frequency)	-

(continued)

TABLE 1. (CONTINUED)

Author, year	Country	No. of subjects <sup>a</sup>	Parents no. (%) <sup>b</sup>	Bereaved no. (%) <sup>c</sup>	Patients	Setting	Items (no.)	Constructs measured	Reliability and validity
Kosco et al., 2000	USA	90 (45 relatives, 45 nurses)	4 (8%)	-	Adult	ICU	45	Importance of needs; needs met (frequency)	-
Browning et al., 2006	USA	30	-	-	Adult	ICU	45	Needs met (frequency)	-
Maxwell et al., 2007	USA	50 (20 relatives, 30 nurses)	-	-	Adult	ICU	30	Importance of needs; needs met (frequency)	ICR $\alpha = 0.93$
Omari, 2009	Jordan	139	+ (% ND)	-	Adult	ICU	44	Importance of needs; needs met (frequency)	Arabic version; CCFNI ICR $\alpha = 0.88$ for total scale; ICR $\alpha = 0.6-0.83$ for the 5 domains; NMI ICR $\alpha = 0.92$ for total scale; ICR $\alpha = 0.68-0.82$ for the 5 domains
Sturdivant et al., 2009	USA	20	14 (70%)	-	Pediatric	PICU	45	Needs met (frequency)	-
Johnson et al., 1998	Canada	115	18 (16%)	+ (% ND)	Adult	ICU	14	Needs met (satisfaction)	Factor analysis yields 4 domains; ICR $\alpha = 0.76$ for total scale
Azoulay et al., 2001	France	895	210 (23%)	+ (% ND)	Adult (84%)	ICU & PICU	14	Needs met (satisfaction)	-
Azoulay et al., 2003	France	3298 (544 relatives, 2754 ICU staff)	103 (19%)	+ (% ND)	Pediatric (16%) Adult	ICU	14	Needs met (satisfaction)	-
Auerbach et al., 2005	USA	40	-	-	Adult	Surgical ICU	14	Needs met (satisfaction)	Satisfaction scale ICR $\alpha = 0.9$ for admission data, $\alpha = 0.9$ for discharge data
Damghi et al., 2008	Morocco	194	20 (10%)	-	Adult	ICU	14	Needs met (satisfaction)	Arabic version; ICR $\alpha = 0.74$ for total scale
Punthamatharith et al., 2007	Thailand	420	420 (100%)	-	Infants	NICU	75	Importance of need; need response; satisfaction with response	Content validity—experts; ICR $\alpha = 0.92$ for importance of needs, $\alpha = 0.97$ for need response, $\alpha = 0.97$ for satisfaction with response

<sup>a</sup>Total sample size (all are family members unless otherwise specified).

<sup>b</sup>Number and percentage of parents in family sample.

<sup>c</sup>Number and percentage of bereaved in family sample.

+, factor present; -, factor not present or not described.

ND, not described; ICR, internal consistency reliability;  $\alpha$ , Cronbach's  $\alpha$  PICU, pediatric intensive care; NICU, neonatal intensive care.

TABLE 2. MAJOR TOOLS AND RELATED ARTICLES USED TO ASSESS PICU AND NICU PARENTS AND NEED-RELATED CONSTRUCTS

<i>Author, year</i>	<i>Country</i>	<i>No. of subjects<sup>a</sup></i>	<i>Parents no. (%)<sup>b</sup></i>	<i>Bereaved no. (%)<sup>c</sup></i>	<i>Patients</i>	<i>Setting</i>	<i>Items (no.)</i>	<i>Constructs measured</i>	<i>Reliability and validity</i>
Wasser et al., 2001	USA	145	+ (%ND)	-	Adult	ICU	20	Satisfaction with care	Content validity—experts; Factor analysis yields 5 domains; ICR $\alpha=0.91$ for total scale; Subscale-total correlations 0.75–0.91; Interscale correlations 0.47–0.88
Wasser et al., 2004	USA	2494	613 (25%)	-	Adult (% ND) Pediatric (% ND)	ICU, PICU & NICU	20	Satisfaction with care	Validation of CCFSS total score by comparison of models developed from initial data (Wasser, 2001) and current data
Latour et al., 2009	Netherlands	559	559 (100%)	-	Pediatric	PICU	78	Importance of satisfaction items	Content validity—experts; Factor analysis yields 5 domains; ICR $\alpha=0.79$ – $0.94$ for the 5 domains; item-total correlations 0.4–0.83
Latour et al., 2010	Netherlands	1218	1218 (100%)	-	Pediatric	PICU	65	Extent of agreement with item	Factor analysis yields 5 domains; ICR $\alpha=0.73$ – $0.93$ for the 5 domains; Congruent validity-Spearman's rank correlations with 4 overall satisfaction statements (0.40–0.58)
Mitchell-Dicenso et al., 1996	Canada	832	832 (100%)	-	Infants	NICU	27	Satisfaction with care	Content validity—experts; test-retest reliability 0.71; Construct validity-NIPS correlation with global satisfaction score 0.61, NIPS correlation with staff perceptions of parent satisfaction 0.15 (mothers) and 0.16 (fathers)
Wielenga et al., 2006	Netherlands	46	46 (100%)	-	Infants	NICU	62	Satisfaction with care	Content validity—experts; 9 investigator derived subscales; ICR $\alpha=0.52$ – $0.67$ for 4 subscales and $>0.7$ for 5 subscales
Gray et al., 2000	USA	30 families	(100%)	-	Infants	NICU	80	Satisfaction with care	-
McCormick et al., 2008	USA	621	621 (100%)	-	Infants	NICU	12	Satisfaction with care	ICR $\alpha=0.89$ for total scale
Carter et al., 1989 and Miles et al., 1989	USA	510	510 (100%)	-	Pediatric	PICU	36	Environmental stress	Content validity—experts; Factor analysis yields 7 domains; ICR $\alpha=0.95$ for total scale; ICR $\alpha=0.72$ – $0.99$ for the 7 domains; Construct validity-7 subscales correlate with state anxiety scores (correlation coefficients 0.29–0.42)

(continued)

TABLE 2. (CONTINUED)

<i>Author, year</i>	<i>Country</i>	<i>No. of subjects<sup>a</sup></i>	<i>Parents no. (%)<sup>b</sup></i>	<i>Bereaved no. (%)<sup>c</sup></i>	<i>Patients</i>	<i>Setting</i>	<i>Items (no.)</i>	<i>Constructs measured</i>	<i>Reliability and validity</i>
Board et al., 2002	USA	31	63 (100%)	4 (6%)	Pediatric	PICU & ward	79	Environmental stress	PICU group: ICR $\alpha = 0.9$ for total scale; ICR $\alpha = 0.48-0.87$ for the 7 subscales; Ward group: ICR $\alpha = 0.94$ for total scale; ICR $\alpha = 0.39-0.86$ for the 7 subscales
Colville et al., 2006	England	34	34 (100%)	-	Pediatric	PICU	36	Environmental stress	-
Miles et al., 1998	USA Canada	190	190 (100%)	-	Parental Stressor Scale-NICU Infants NICU	PSS-NICU NICU	46	Environmental stress	Content validity-experts; Factor analysis yields 3 domains; ICR $\alpha = 0.89$ for total scale; ICR $\alpha > 0.7$ for the 3 domains; Item-total correlations 0.35-0.81; interscale correlations 0.34-0.92; Construct validity-3 subscales correlate with state anxiety scores (correlation coefficients 0.44-0.45)
Miles et al., 2003	USA	124	124 (100%)	-	Parental Stressor Scale-Infant Hospitalization (PSS-IH) Infants	PICU, NICU & inter-mediate care	22	Environmental stress	Content validity-experts; 3 subscales; ICR $\alpha = 0.87$ for total scale (mothers) and 0.9 (fathers); ICR $\alpha > 0.7$ for the 3 subscales; Subscale-total correlations 0.72-0.89; interscale correlations 0.41-0.64; Construct validity-3 subscales and total scale correlate with maternal worry and depression Chinese version: ICR $\alpha = 0.91$ for total scale (mothers) and 0.92 (fathers)
Lee et al., 2007	USA	55	55 (100%)	-	Infants	PICU & NICU	26	Environmental stress	

<sup>a</sup>Total sample size (all are family members unless otherwise specified).

<sup>b</sup>Number and percentage of parents in family sample.

<sup>c</sup>Number and percentage of bereaved in family sample.

+, factor present; -, factor not present or not described.

ND, not described; ICR, internal consistency reliability;  $\alpha$ , Cronbach's  $\alpha$ ; PICU, pediatric intensive care; NICU, neonatal intensive care.

TABLE 3. MAJOR TOOLS AND RELATED ARTICLES USED TO ASSESS PARENT NEEDS ON GENERAL PEDIATRIC WARDS

Author, year	Country	No. of subjects <sup>a</sup>	Parents no. (%) <sup>b</sup>	Bereaved no. (%) <sup>c</sup>	Patients	Setting	Items (no.)	Constructs measured	Reliability and validity
Kristjansdottir, 1995	Iceland	34	34 (100%)	-	Pediatric	General ward	43	Importance of needs; fulfillment; independence in meeting need	Content validity—experts; ICR $\alpha = 0.92$ for importance scale; $\alpha = 0.95$ for fulfillment scale; $\alpha = 0.91$ for independence scale
Shields et al., 2003, 2004	Sweden	245 (113 parents, 132 staff)	113 (100%)	-	Pediatric	General ward	51	Importance of needs; fulfillment; independence in meeting need	Swedish version; ICR for parent: $\alpha = 0.92$ for importance scale, $\alpha = 0.94$ for fulfillment scale, $\alpha = 0.96$ for independence scale; ICR for staff: $\alpha = 0.96$ for fulfillment scale; $\alpha = 0.96$ for independence scale
Shields et al., 2004	England	158 (85 parents, 73 staff)	85 (100%)	-	Pediatric	General ward	51	Importance of needs; fulfillment; independence in meeting need	ICR $\alpha = 0.92$ for importance scale; $\alpha = 0.94$ for fulfillment scale; $\alpha = 0.96$ for independence scale
Kyritsi et al., 2005	Greece	103	103 (100%)	-	Pediatric	General ward	43	Importance of needs; fulfillment; independence in meeting need	-
Shields et al., 2008	Australia	209 (130 parents, 79 staff)	130 (100%)	-	Pediatric	General ward	51	Importance of needs; fulfillment; independence in meeting need	ICR $\alpha = 0.91$ for both parent and staff versions

<sup>a</sup>Total sample size (all are family members unless otherwise specified).

<sup>b</sup>Number and percentage of parents in family sample.

<sup>c</sup>Number and percentage of bereaved in family sample.

+, factor present; -, factor not present or not described.

ND, not described, ICR, internal consistency reliability;  $\alpha$ , Cronbach's  $\alpha$ .



TABLE 4. MAJOR TOOLS AND RELATED PAPERS USED TO ASSESS BEREAVED PARENTS AND NEED-RELATED TOPICS

Author, year	Country	No. of subjects <sup>a</sup>	Parents no. (%) <sup>b</sup>	Bereaved no. (%) <sup>c</sup>	Patients	Setting	Items (no.)	Constructs measured	Reliability and validity
Seecharan et al., 2004	USA	79	79 (100%)	79 (100%)	Pediatric	Hospital	35	Satisfaction with care	ICR $\alpha = 0.54-0.9$ for the 10 scales
Heyland et al., 2001	Canada	47	4 (9%)	22 (47%)	Adult	ICU	34	Satisfaction with care and decision-making	Content validity—experts; Satisfaction with care—4 investigator-derived domains, ICR $\alpha = 0.74-0.97$ for the 4 domains; Satisfaction with decision-making-2 domains, ICR $\alpha = 0.87$ and $0.93$ for the 2 domains; test-retest reliability (Spearman's correlation = $0.85$ )
Wall et al., 2007	Canada & US	1,038	108 (10%)	+ (% ND)	Adult Pediatric	ICU & Burn-PICU	24	Satisfaction with care and decision making	Construct validity—factor analysis yields 2 domains; Item-subscale correlations $0.38-0.79$ ; ICR $\alpha = 0.94$ for total scale; ICR $\alpha = 0.92$ and $0.88$ for the 2 domains; FS-ICU correlated with Family QODD <sup>d</sup> total score, single QODD items and multiple nurse assessed quality indicators.
Wall et al., 2007	US	539	88 (16%)	275 (51%)	Adult	ICU	24	Satisfaction with care and decision making	-
Gries et al., 2008	US	356	17 (5%)	356 (100%)	Adult	ICU	10	Satisfaction with decision making	-
Curtis et al., 2008	US	275	+ (% ND)	275 (100%)	Adult	ICU	24	Satisfaction with care and decision making	-

<sup>a</sup>Total sample size (all are family members unless otherwise specified).

<sup>b</sup>Number and percentage of parents in family sample.

<sup>c</sup>Number and percentage of bereaved in family sample.

<sup>d</sup>Quality of Death and Dying Questionnaire.

+, factor present; -, factor not present or not described.

ND, not described; ICR, internal consistency reliability;  $\alpha$ , Cronbach's  $\alpha$ .

need-related constructs such as satisfaction or environmental stress.

The Critical Care Family Satisfaction Survey (CCFSS) was developed to measure family and patient satisfaction with critical care.<sup>57,58</sup> Of the 20 items, some relate to family needs and others to both family and patient needs. Each item is rated on a 5-point scale from "very dissatisfied" to "very satisfied." Factor analysis yielded 5 domains including assurance, proximity, information, comfort and support. Validity of the total CCFSS score has been supported in a large population of relatives of critically ill infants, children, and adults.<sup>58</sup>

The Empowerment of Parents in the Intensive Care (EMPATHIC) survey is a 65-item instrument designed to measure parent satisfaction in the PICU.<sup>59-62</sup> Respondents rate the extent of agreement with each item on a 6-point scale from "certainly no" to "certainly yes." Factor analysis yielded 5 domains including information, care and cure, organization, parental participation, and professional attitude. EMPATHIC scores showed moderate correlation with parents' responses to four global satisfaction statements. Bereaved parents were not included.

The Neonatal Index of Parent Satisfaction (NIPS) was designed to measure parent satisfaction in the NICU.<sup>63,64</sup> Of the 27 items, 17 reflect unmet needs and 9 reflect needs met. Respondents report frequency of occurrence of each item on a 7-point scale from "none of the time" to "all of the time." Three subscales include confidentiality/quality of care, communication, and attitude/caring/personality. NIPS scores correlated highly with parents' global rating of satisfaction and weakly with staff's perceptions of parent satisfaction.

The NICU Parent Satisfaction Form (NICU-PSF) has 62 items measuring satisfaction, continuity of care, communication and information, preparedness, involvement in care, being a parent, being near the baby, support, and follow-up.<sup>64,65</sup> Various response scales are used for different sets of items (e.g., degree of satisfaction, frequency of occurrence). The NICU-PSF was used to assess parent satisfaction in an interventional trial of a family-centered care program.<sup>65</sup> Overall satisfaction was higher with the intervention than traditional care.

The Picker Institute NICU Family Satisfaction Survey is an 80-item tool designed to measure parent satisfaction across the continuum of NICU care from pre-delivery through post-discharge follow-up.<sup>64,66</sup> No published psychometric data for the 80-item survey were identified. A 12-item tool was adapted from the Picker survey to assess parent satisfaction with staff availability, emotional support, information, NICU rules, and facilities.<sup>67</sup> Respondents rate each item on a 5-point scale from "poor" to "excellent." Using the 12-item tool, predictors of parent satisfaction included the infant's health 3 months postdischarge and sociodemographic factors.

The Parental Stressor Scale: Pediatric Intensive Care Unit (PSS:PICU) was designed to assess parents' perceptions of stress related to the physical and psychosocial environment of the PICU.<sup>68,69</sup> Based on stress theory, the original PSS:PICU had 79 items derived from clinical observation, interviews, and literature review which were later reduced to 36. Respondents rate the level of stress associated with each item on a 5-point scale from 'not stressful' to 'extremely stressful.' Factor analysis yielded 7 stress domains including the child's behavior and emotions, child's appearance, sights and sounds, procedures, staff communication, anomie, and pa-

rental role alteration. Construct validity was demonstrated by correlations between the PSS:PICU and state anxiety scores.

In a PSS:PICU study conducted in 5 U.S. PICUs, elements of the child's behavior and emotions domain (e.g., seeing the child in pain) and parental role alteration (e.g., feeling unable to protect the child) were rated as most stressful by parents.<sup>69</sup> Aspects of the physical environment were least stressful. Additional work with the PSS:PICU demonstrated relationships between parental stress and family functioning<sup>70</sup> and posttraumatic stress disorder.<sup>71</sup>

Recognizing that parental stressors vary depending on the child's age and care setting, the PSS was adapted for use in the NICU (PSS:NICU)<sup>72</sup> and for infant hospitalization (PSS:IH).<sup>73,74</sup> The PSS:NICU has 46 items. Factor analysis yielded 3 domains including infant behavior and appearance, parental role alteration, and sights and sounds of the unit. PSS:NICU scores correlated with state anxiety scores. The PSS:IH has 22 items in the same 3 domains. PSS:IH scores correlated with indices of maternal worry and depression post-discharge.

### **Parent needs on pediatric wards**

The Needs of Parents Questionnaire (NPQ) has dominated assessment of parents' needs during a child's hospitalization on a general ward. The NPQ was originally designed as a 43-item tool for use with parents of 2-6 year old children.<sup>75-77</sup> Later, 8 items were added and the NPQ was used with parents of children from birth to 18 years of age.<sup>78-81</sup> Items are divided into 6 categories including the need to trust doctors and nurses, information, needs related to other family members, feeling trusted, human and physical resources, and support and guidance. Parents respond to each item on 3 scales: (1) a 5-point rating of need importance, (2) a 3-point rating of need fulfillment, and (3) a yes/no report of whether help was required to meet the need. NPQ studies have shown that parents rank the need to trust and the need for information higher than the need for physical resources and support.<sup>76,79</sup> Parents also declare themselves more independent at meeting their needs than staff perceive them to be.<sup>78,79,81</sup> NPQ studies have routinely excluded PICU parents.

### **Bereaved parents and need-related constructs**

None of the instruments described thus far focus on the needs of families bereaved in the hospital. Two instruments warrant review because they have been used with bereaved parents to assess need-related constructs in the PICU or related hospital settings.

The 61-item Comprehensive Assessment of Satisfaction with Care (CASC) was originally designed to assess adult cancer patients' perceptions of the quality of care received in oncology hospitals.<sup>82-85</sup> More recently, the 35-item CASC-Short Form has been used to assess parent satisfaction with care after a child's death in the hospital.<sup>86</sup> The tool has 10 scales to assess physicians (technical skills, interpersonal skills, information, and availability), nurses (technical skills, information, and availability), care organization, access and comfort, and general satisfaction. Respondents rate each item on a 5-point scale from "poor" to "excellent." Parents' satisfaction was unrelated to their grief intensity partly due to high satisfaction scores that constrained variance.<sup>86</sup> The call was

made for evaluating parents' experiences rather than satisfaction when exploring relationships between care and grief outcomes.

The Family Satisfaction in the Intensive Care Unit (FS-ICU) survey was developed to measure satisfaction with family and patient care in ICUs.<sup>87-91</sup> Based on conceptual frameworks of patient satisfaction, quality of end-of-life care, needs of families of critically ill patients and decision making, the original 34-item tool was designed in 2 parts including satisfaction with care and satisfaction with decision making.<sup>87</sup> Refinement of the tool reduced the number of items to 24 and confirmed the two domains.<sup>88</sup> Respondents rate each item on a 5-point scale from "poor" to "excellent." FS-ICU scores were shown to correlate with family perceptions of the quality of end of life care in ICUs using the Quality of Death and Dying (QODD) questionnaire.<sup>88,92</sup> FS-ICU scores did not correlate with nurse QODD scores suggesting that family and nurse perceptions of quality differ.

## Discussion

The purpose of this review was to identify and evaluate instruments potentially useful for assessing the needs of bereaved parents in PICU. We identified tools that purport to measure family needs, satisfaction with family care, and family stressors in ICUs and other hospital settings. However, no tools were specifically intended to assess the needs of parents whose children die in PICU or the extent to which these parents perceive their needs as met. Such a tool is required to design and evaluate family-centered interventions aimed at meeting parents' needs during a child's critical illness and death, and to study the relationships between family care and bereavement outcomes.

Some instruments were excluded from our review because they were primarily designed to assess patient needs using family members as proxies.<sup>93-95</sup> However, the distinction between patient and family needs is not always clear. For example, terminally ill children have a need for pain control and parents have a need to feel that their child's pain is adequately treated. Because of the overlap between patient and family needs, we reviewed the items of each tool to determine the overall focus; tools mainly assessing patient needs were excluded. Some tools were excluded because they were developed and tested among relatives of elderly adults receiving end-of-life care at home or in adult hospital settings which differ in patient conditions, illness trajectories and life course perspectives.<sup>94-99</sup>

Although the reviewed instruments describe validity and reliability in the settings and populations for which they were designed or adapted, psychometrics have not been established for bereaved parents in the PICU. Many domains of family need included in the tools such as assurance, information and proximity were also identified in prior qualitative work with bereaved parents.<sup>12-14</sup> However, specific needs within these domains may differ in the death context. For example, a proximity need for bereaved parents may be presence at the time of death; an information need may be to understand the cause of death; and an assurance need may be for staff to acknowledge the loss. Other domains identified in qualitative work such as the need for a reverent atmosphere at the time of death were not well represented in the tools.<sup>12</sup>

Most of the tools reviewed demonstrate construct validity by factor analysis and/or relationships with theoretically-

related measures. Establishing construct validity of a needs assessment tool for bereaved parents should involve demonstration of relationships between the tool and measures specific to bereavement such as those assessing intensity and duration of grief, or complicated grief. Further exploration of these relationships would help to elucidate ways in which family care provided in the PICU affects parents' grief trajectories.

Multiple investigators have assessed family needs from the perspectives of both families and ICU staff.<sup>18,20,22,29,30,32-34,37,46,48,53,78,79,81</sup> Consistently across studies, families and staff perceive family needs differently. A tool to assess bereaved PICU parents' needs should be designed as a self-report measure to assess parents' needs directly rather than through proxies.

Limitations of this review include the possibility that our search strategy did not identify all instruments potentially useful for assessing the needs of bereaved PICU parents. Of the tools reviewed, not all papers using these tools are described. Strengths include the systematic presentation of validity and reliability estimates and examples of the various tools' performance in settings and populations related to the PICU.

Further research should design a needs assessment tool for parents bereaved in the PICU in which the domains and items are based on these parents' lived experiences and perspectives. Further research should also establish the psychometrics of this new tool within the bereaved PICU parent population. Such a tool would allow investigation of the relationships between parents' met and unmet needs and their bereavement outcomes.

## Conclusion

We conclude that a new tool is needed to assess bereaved parents needs in the PICU. Although commonalities exist across neonatal, pediatric and adult ICUs, differences in patient conditions, illness trajectories and life course perspectives must be considered in designing a new tool.

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