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## SECTION 2: MEASUREMENT

### Neonatal Intensive Care: Satisfaction Measured From a Parent's Perspective

Jeanette M. Conner, MS, MN\*; and Eugene C. Nelson, DSc, MPH‡

**ABSTRACT.** Health care systems today are complex, technically proficient, competitive, and market-driven. One outcome of this environment is the recent phenomenon in the health care field of "consumerism." Strong emphasis is placed on customer service, with organized efforts to understand, measure, and meet the needs of customers served. The purpose of this article is to describe the current understanding and measurement of parent needs and expectations with neonatal intensive care services from the time the expectant parents enter the health care system for the birth through the discharge process and follow-up care. Through literature review, 11 dimensions of care were identified as important to parents whose infants received neonatal intensive care: assurance, caring, communication, consistent information, education, environment, follow-up care, pain management, participation, proximity, and support. Five parent satisfaction questionnaires—the Parent Feedback Questionnaire, Neonatal Index of Parent Satisfaction, Inpatient Parent Satisfaction—Children's Hospital Minneapolis, Picker Institute-Inpatient Neonatal Intensive Care Unit Survey, and the Neonatal Intensive Care Unit-Parent Satisfaction Form—are critically reviewed for their ability to measure parent satisfaction within the framework of the neonatal care delivery process. An immense gap was found in our understanding about what matters most and when to parents going through the neonatal intensive care experience. Additional research is required to develop comprehensive parent satisfaction surveys that measure parent perceptions of neonatal care within the framework of the care delivery process. *Pediatrics* 1999;103:336–349; *parent satisfaction, questionnaires, neonatal intensive care, pediatric.*

ABBREVIATIONS. NICU, neonatal intensive care unit; NIPS, Neonatal Index of Parent Satisfaction; NICU-PSF, NICU Parent Satisfaction Form; SD, standard deviation.

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Health care systems today are characterized as complex, in flux, technically proficient, competitive, and market-driven. One outcome of this environment is the recent phenomenon in the health care field of "consumerism." Strong emphasis is being placed on customer service, with organized efforts to understand, measure, and meet the needs of customers served. Evidence of this phenomenon is found in the numerous publications that focus on patient satisfaction as a key outcome measure of health care. Patient satisfaction, defined as the perception of patient needs and expectations being met, is rapidly becoming a primary indicator for evaluation and comparison of quality in health care plans.<sup>1,2</sup> Currently, efforts are underway in the national accrediting organizations for unified, standardized patient satisfaction measures, thus supporting the importance of measurement of customer needs and expectations. One newly developed satisfaction survey, Consumer Assessment of Health Plans, is being lobbied widely as a leading instrument for comprehensive measurement of patient (adult) satisfaction and for standardized comparisons of quality health plans.<sup>3–6</sup>

#### AIM

The aim of this article is to describe the current understanding and measurement of parent needs and expectations of neonatal intensive care services from the time the expectant parents enter the health care system for the birth through the discharge process and follow-up care. This article reviews the pediatric satisfaction literature, with particular attention to neonatal care, addresses known concepts of care that are important to families, critically reviews parent satisfaction questionnaires, and offers recommendations for future studies.

#### CONCEPTUAL FRAMEWORK

##### The Clinical Value Compass Approach

Important studies have been conducted to provide a theoretic yet "actionable" framework in which multiple outcomes of health care can be viewed as a process of care.<sup>7,8</sup> This work has expanded our thinking from measuring purely clinical outcomes to measuring clinical and functional outcomes, patient satisfaction, and cost of care within the framework of the care delivery process. The process involves an episode of care beginning with patient entry into the health care system with needs and expectations and

ends when the health care needs and expectations have been met (Fig 1). The episode of care begins with an expression of a need, such as an infant born prematurely and admitted to the neonatal intensive care nursery. The Clinical Value Compass on entry into the health care delivery process models the initial state of the infant, including sociodemographic characteristics and four health outcomes: clinical, functional, patient (or parent) expectations, and cost. The Clinical Value Compass points (Fig 2) north, east, south, and west refer to the four health outcomes: functional health status, satisfaction against need, total costs, and clinical outcomes. Functional health status includes measurement of physical and mental abilities and social-emotional and role-functioning. Measuring expectations with the delivery of health care services can include measuring satisfaction with a procedure, a single patient visit, or an entire hospital stay. Measurement of the costs of health care includes both the direct costs (eg, expenditures for medical care) and the indirect costs of care such as time lost from studies. Clinical status includes such measures as the presence or absence of a disease state, or physiologic parameters. The four Clinical Value Compass points provide a complete "picture" of patient needs and expectations at both

the entry and the exit points of the health care delivery process.

#### CARE DELIVERY PROCESS FOR NEONATAL INTENSIVE CARE

Measuring satisfaction of a hospital stay needs to be performed within the framework of the health care delivery process. In other words, it is necessary to know at what point along the continuum of care certain aspects of care have greater weight and importance to parents. This is valuable for two reasons: first, the information gained is useful for targeting quality improvement efforts, and second, the information allows for judgment or comparison of the quality of health care services delivered. Furthermore, by understanding where in the delivery process certain aspects of care are most important to parents, standardized comparisons can be made across health care plans.

It is assumed that a basic continuum of care delivery exists for the neonatal patient; this continuum can be described by distinct stages (Fig 3). The process begins before the infant is born, when parents anticipate the arrival of a "potentially" critical infant and envision uncertainty in events that may not be realized. Because this period has been identified as

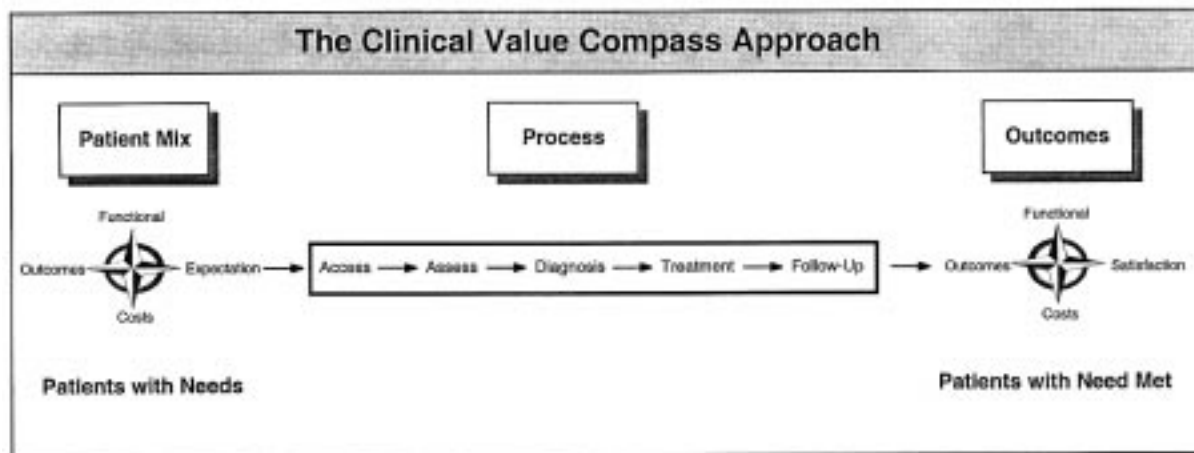
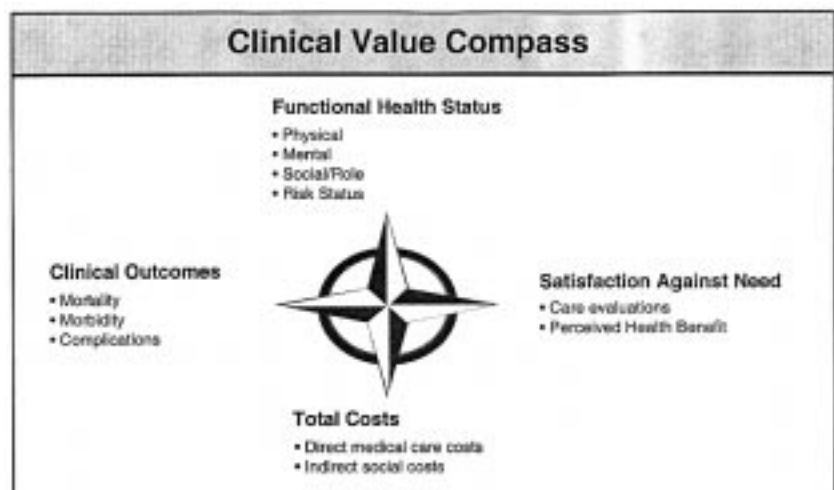


Fig 1. The Clinical Value Compass illustrates the flow of the care delivery process and its results.

Fig 2. The Clinical Value Compass models four health outcomes: functional health status, patient satisfaction, total costs, and clinical outcomes.



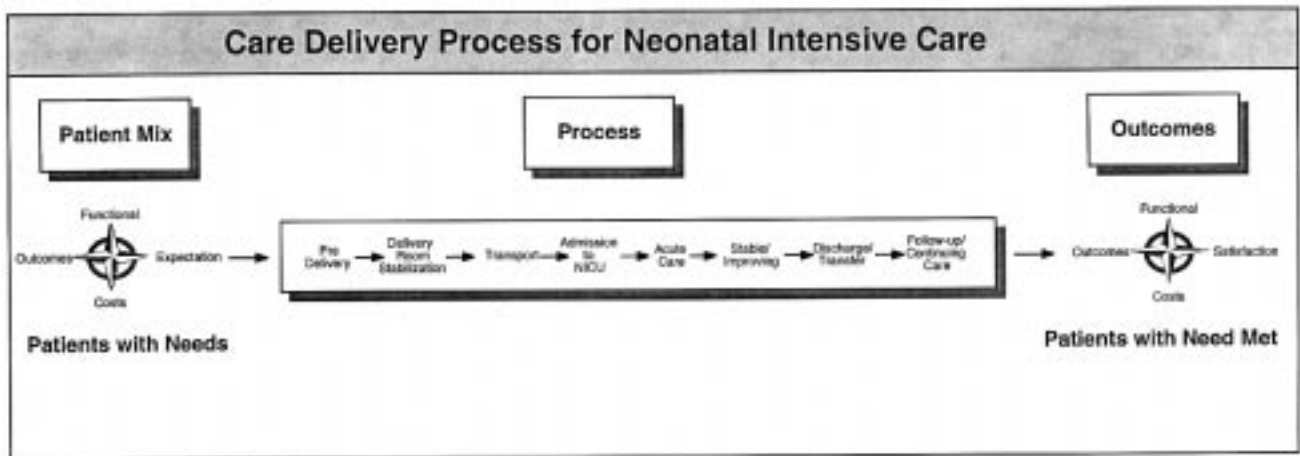


Fig 3. The Continuum illustrates the neonatal intensive care delivery process. Some infants may be transported for admission to the NICU after delivery and stabilization elsewhere.

anxiety-provoking and important to parents,<sup>9</sup> it is the entry point for the neonatal continuum of care. The second step in the care delivery process is delivery room stabilization. From this point, care may flow directly into admission to the neonatal intensive care unit (NICU), or may involve a neonatal transport before NICU admission. The following stages in care delivery are defined as an acute/critical care phase, a stable-improving phase, a transfer-discharge phase, and a follow-up or continuing care phase. Frequently, there are feedback loops, when an infant may move back to a previous stage, such as moving back to an acute stage having once been stable and improving.

#### LITERATURE REVIEW

The care delivery process provides a framework to parents and families who receive health care services for thinking about what matters most and at what time. The literature review addresses the current state of knowledge of parent satisfaction with pediatric and neonatal health care services in the context of identifying concepts that matter within the framework of the care delivery process. The purpose of this review is to identify content areas of care to measure satisfaction and improve care delivery; it is not meant to reflect "bad" care delivery and dissatisfied parents.

Patient satisfaction with adult health care services is not a new concept. There is an extensive body of adult patient satisfaction literature with many validated surveys available for measurement. In the pediatric and particularly the neonatal literature, there is scarce information that identifies important aspects of health care services to parents with only a handful of validated surveys available to measure parent satisfaction. A review of the literature was performed using the search engine OVID for the years 1988 to 1998. BIOSIS, CINAHL, HEALTHSTAR, and MEDLINE were searched using the following key terms: patient satisfaction, parent satisfaction, and consumer satisfaction. The search was cross-referenced with the terms pediatric and infant-newborn. Fifty-five

studies were identified to be relevant to parent satisfaction with pediatric and neonatal health care services. Criteria for relevance were those studies in which concepts of health care services were recognized as important to parents or in which parent satisfaction was measured within a hospital experience. These criteria were chosen because we believed they would identify aspects of care delivery that mattered to parents within the continuum of care delivery. Of the 55 studies, only 11 identified or measured aspects of neonatal health care services. The pediatric and neonatal literature is reported separately within the framework of the care delivery process. Because of the limited information available on parent satisfaction with neonatal care, the pediatric literature is reported first, because it contains concepts similar to those in the neonatal literature.

#### Concepts of Parent Satisfaction: Pediatric

Table 1 summarizes aspects of pediatric health care reported by parents to matter while their child received services. Seventeen constructs of health care services were identified by parents as important enough to impact satisfaction reports (Table 1). These included access to provider, wait time, interpersonal relationships, support, chronic long-term care, information-giving, anticipatory guidance, competency of medical and nursing care, professional appearance, consistency of care, atmosphere, pain management, participation in decision-making, involvement in care, parent presence, and parent roles. Many of these aspects reflected similar concepts and, consequently, were combined into nine categories: access, caring, chronic care, communication, competency of care, continuity of care, environment, pain management, and participation in care.

The following constructs are identified in the literature.

#### Access, Wait Time

Parents who took their children to an emergency department were surveyed with an eight-item Client Satisfaction Questionnaire about quality and satisfac-



**TABLE 1.** Concepts of Caregiving Identified as Important to Families Whose Children Received Pediatric Health Care Services

Aspects of Caregiving	References
Access	10, 37–40
Accessibility of provider	
Wait time	
Caring	11, 41, 42
Interpersonal relationships	
Support, emotional needs	
Chronic care	10, 12, 43
Chronic long-term care	
Communication	10–12, 17–20, 22, 23, 29,
Information giving	38, 42, 44–50
Guidance, preparedness	
Competency	19, 21, 23, 51–53
Medical care	
Nursing care	
Professional appearance	
Continuity	10, 22, 51
Consistency of care	
Environment	23
Atmosphere	
Pain management	22
Participation	17, 24, 25, 41, 54
Decision-making	
Involvement in care	
Parent presence	
Parent roles	

tion with care. Of the 141 parents responding to the survey (89% response rate), 27% were less satisfied when they perceived that their child was not attended to quickly enough. The median wait time for less satisfied parents was twice that of the satisfied parent group (median, 85 minutes; range, 2 to 210 minutes;  $P = .001$ ). A total of 125 parents of chronically ill children reporting on 22 components of care ranked accessible and available health care services in the top two categories of a five-point importance scale.<sup>10</sup>

#### Caring

A sympathetic physician has been reported to be a significant contributor to parent satisfaction.<sup>11</sup> A total of 166 parents of children with disabilities were asked to recall the interaction when they were first told of their child's disabilities. Factor analysis was performed to identify and correlate parent satisfaction with physician affect. Results demonstrated that a sympathetic physician was the most important predictor of parent satisfaction (35.7% of variance;  $P < .001$ ).

#### Chronic Long-term Care

Parents of chronically ill children ranked many other components of care in the top two categories, including continuity and consistency of care, diagnosis, education and information, evaluation of chronic illness, parent involvement, and treatment of chronic illness.<sup>10</sup> Other studies have reported similar findings.<sup>12–14</sup> Some parents have reported greater satisfaction with having a technologically dependent child at home than hospitalized.<sup>13</sup>

#### Communication

Communication is the most reported domain of satisfaction with pediatric health care services. Sev-

eral dimensions of communication have been identified, such as open and honest dialogue, sharing of factual information, providing complete information, and preparing parents for uncertainty. Parents want medical information communicated in a meaningful way that is interpretable to them.<sup>14–16</sup> The way in which communication is delivered impacts parent perception and satisfaction of the interaction, a sympathetic approach being most favorable.<sup>11</sup> Parents also want to be prepared for potential events and outcomes and, in some circumstances, parents prefer written guidelines when there is an expectation that their child will not survive.<sup>15,17,18</sup>

#### Competency

In a report of parents' perceptions of children's care while hospitalized for treatment of HIV/AIDS, parents stated they had greater satisfaction with the expertise of the pediatric specialist and less confidence in the care of the generalist at a nonspecialty hospital.<sup>17</sup> Competence and appearance of emergency department care providers was found to be relevant in parent perceptions of care provided.<sup>19</sup> Parents preferred a formal appearance over scrubs, although appearance did not necessarily equate with a less competent provider.

#### Continuity of Care

Consistency in care matters to parents of acute and chronically ill children. Parents of critically and chronically ill children report less satisfaction with health care when there is a lack in continuity of care providers.<sup>10,20</sup>

#### Environment

One article addressed the health care atmosphere and its effects on parent satisfaction.<sup>21</sup> A small percentage of parents (1%) were dissatisfied with the pediatric rheumatology ward where their child received care, whereas 35% were satisfied and 64% were very satisfied. Some parents commented on the desire for better facilities for the younger children (1 to 2 years of age) and for a quieter environment.

#### Pain Management

Pain management was reported as a problem affecting perceived quality of care by pediatric cancer patients and parents.<sup>20</sup> Pain during examination and induction of chemotherapy were sources of dissatisfaction for the pediatric patient. Survey results demonstrated that parents perceived their child's pain as less than did their child and thus parents were more satisfied with pain management.

#### Participation

Parent involvement in care, particularly in the decision-making process over critical life decisions, was felt by 92% of parents of children with special needs to be best made through discussions with parents and physicians.<sup>15</sup> Parent presence during anesthesia induction was evaluated with an experimental design to determine the effect on parent anxiety and satisfaction.<sup>22</sup> Parents were randomly assigned to the experimental group ( $n = 41$ ) and control group ( $n =$

34). No difference in satisfaction was found between parents who were present during induction and those who were not ( $P = .116$ ). Other researchers report that parent participation in the care process is important to parent perceptions of care received.<sup>10,23</sup>

#### Procedures

There are a number of pediatric studies that include parent reports of satisfaction with specific medical procedures, ranging from type of anesthesia for pain management to surgical procedures (Table 2).

#### Concepts of Parent Satisfaction: Neonatal

It is clear from the literature that parent satisfaction is a multidimensional concept. Many of the concepts represented in the pediatric satisfaction literature are found consistently in the neonatal literature. Eleven studies found in the literature explore 11 dimensions of neonatal care services and identify five neonatal parent satisfaction questionnaires (Table 3). The constructs analyzed include assurance, caring, communication, consistent information, education, environment, follow-up care, pain management, participation in care, proximity, and support. These dimensions were identified through exploratory and focused interviews and through survey administration. Baas interviewed 36 married Caucasian parents older than 18 years of age to determine self-reported needs.<sup>24</sup> Through content analysis, 13 categories were identified; those most frequently regarded as important were information, person-related support, attachment/parenting, physical support, spiritual support, and staff support. Able-Boone and colleagues investigated parent perceptions of the NICU experience via open-ended focused interviews of health care providers and parents.<sup>25</sup> Through an in-depth content analysis, a taxonomy of domains and related categories were developed that included communication, information, preparing parents, decision-making, parent and staff roles, support, interpersonal relationships, and the NICU environment. Perhaps the most poignant documentation of constructs of neonatal health care services from the parent's perspective is found in the "Principles for Family-centered Neonatal Care."<sup>9</sup> This article was written and published by a group of concerned parents whose infants had received neonatal intensive care services. The parents defined

TABLE 2. Parent Satisfaction With Pediatric Procedures

Procedure	References
Anesthesia, pain management	55-57
Antibiotic therapy	58, 59
Feeding practice	60
Gastroesophageal reflux	61
Gastrostomy button	62
Jejunostomy	63
Physiotherapy	64
Surgical repair	65, 66
Clefts	
Short stay	
Suturing lacerations	67
Sphincterotomy	68

TABLE 3. Concepts of Caregiving Identified as Important to Families Whose Infants Received Neonatal Health Care Services

Concepts	References
Assurance	9, 28
Trust	
Confidence in care	
Caring	9, 28, 29
Interpersonal relationships	
Communication	9, 16, 16-33
Information giving	
Guidance/preparedness	
Consistent information	31
Consistency in care	
Education	31
Environment	9, 26, 32
Conducive to families	
Privacy	
Follow-up care	9, 31, 69
Long term follow up	
Hearing evaluation	
Pain management	9
Participation	9, 16, 27, 31-33
Decision-making	
Involvement in care	
Parent roles	
Proximity	26, 32
Attachment needs	
Closeness	
Support	26, 27, 30, 31, 33
Emotional	
Physical	
Spiritual	

communication, information sharing, decision-making, pain management, NICU environment, efficacious treatments, parent and family involvement, follow-up care, and support as central themes requiring change.

The following constructs were identified in the literature.

#### Assurance

Trust was found to be an important aspect to parents and neonatal care providers who participated in item selection and reduction in the development of a parent satisfaction survey.<sup>26</sup>

#### Caring

The studies of Mitchell-DiCenso and colleagues identified a caring personality as an important domain in parent satisfaction.<sup>26</sup> Caring, such as a sympathetic approach, an opportunity to talk and be heard, and an effort to make parents feel better, has been reported by parents to be favorable approaches to care delivery that impact perceived satisfaction of care.<sup>11,27</sup>

#### Communication

Communication and information is one of the most reported content areas of neonatal care services. Parents whose infants were born with cleft lip and/or palate reported that they wanted more opportunity to talk, show their feelings, have more information given to them, and more time for discussion at the time they learned of their child's diagnosis. Parents wanted the physician to make them feel better and to be more caring and more confident. These parents wanted referrals to other parents for

an opportunity to share with those who had had similar experiences. Similar findings are reported from parents whose infants were diagnosed with a severe disability.<sup>11</sup> A strong positive association was found between the nature and the timing of the interaction. Parents who were told at birth or early in their child's life of the diagnosis were more satisfied than were parents told at later times ( $P < .05$ ), and parents told in a sympathetic manner were more satisfied ( $P < .001$ ). The need for honest and open communication is echoed in two reports.<sup>9,28</sup>

#### *Consistent Information*

Consistency in explanations regarding care was reported in a survey of 171 parents after their infant had received neonatal care.<sup>29</sup> Of respondents, 9% described inconsistencies among staff on instructions regarding maternal involvement in care, and 26% reported inconsistencies about breastfeeding advice. Although these estimates are reported, there is no mention of these influencing parent satisfaction ratings.

#### *Education*

Teaching parents skills to prepare them for discharge has important implications for parents. Thirty-nine percent of parents perceived the teaching to be inadequate, whereas 94% felt they were ready for discharge and were satisfied overall with NICU care.<sup>29</sup>

#### *Environment*

The physical environment, such as needing a place to rest or having food available, has been reported by parents as high ratings of needs.<sup>24</sup> Other parents reported needing a quiet place to rest, a waiting area, and overnight accommodations.<sup>30</sup> As a result of this knowledge, the first area targeted for quality improvement was the NICU environment. One group of parents commented that the NICU environment was "bright, loud, intrusive, frequently painful, and unrelenting."<sup>9</sup> These parents requested that neonatal intensive care environments be altered to protect the infants from unnecessary and invasive stimuli.

#### *Follow-up Care*

Many parents have described the need for comprehensive follow-up services, partly because of the difficulty of finding and coordinating such services and because of the numbers of infants lost to follow-up.<sup>9,25</sup> Other parents described feeling vulnerable after discharge from the NICU because they did not receive home visit follow-up.<sup>29</sup>

#### *Pain Management*

Parents have reported dissatisfaction with their children's unrelieved pain and would like to see ongoing attention paid to discussion and consideration of pain management.<sup>9</sup>

#### *Participation*

Many researchers have identified parental participation in care and decision-making as important elements of parent satisfaction.<sup>9,14,25,31</sup> Parents want to

have the ability to make treatment decisions and are frequently not given the opportunity to do so.<sup>9,14,25</sup> Parents report that "in medical situations involving very high mortality and morbidity, great suffering, and/or significant medical controversy, fully informed parents should have the right to make decisions regarding aggressive treatment for their infants."<sup>9</sup> Satisfaction was found to be significantly higher in parents who were involved in the decision-making process in the management of their infant.<sup>14</sup>

#### *Proximity*

Parents have a need to be close to their infant while the infant is hospitalized. This concept was identified in two parent satisfaction surveys.<sup>24,30</sup>

#### *Support*

Emotional, physical, and spiritual support have been described by researchers to contribute to parent satisfaction of care.<sup>24,25,28,30,31</sup> Parents have reported the need to express their feelings,<sup>25</sup> to feel accepted and cared for,<sup>30</sup> to have a chaplain available,<sup>24,30</sup> and to be able to talk with and express feelings to nurses.<sup>24,30,31</sup>

### NEONATAL PARENT SATISFACTION QUESTIONNAIRES

The five neonatal parent satisfaction questionnaires identified are critically reviewed for their ability to measure parent satisfaction with neonatal care within the framework of the care delivery process. The dimensions critiqued include the survey's purpose, content, items and response categories, reliability, and validity. Two of the questionnaires were found in the literature review: the Parent Feedback Questionnaire<sup>30</sup> and the Neonatal Index of Parent Satisfaction (NIPS).<sup>26</sup> Two surveys were located through networking: the Children's Health Care-Minneapolis Survey of Inpatient Parent Satisfaction and the NICU Picker Survey.<sup>4</sup> The fifth survey, the NICU Parent Satisfaction Form (NICU-PSF), developed by one of the authors (J.M.C.) is reported here. No other survey measuring parent satisfaction with neonatal intensive care could be located through literature review.

The purpose of the critique is to identify what questionnaires are available for use and to identify gaps in parent satisfaction measurement. Each questionnaire is described by reporting the survey's purpose, conceptual basis, and a description of the survey. The questionnaires are critiqued for reliability, or the accuracy and precision of the survey measures. Reliability is measured by internal consistency, or the extent to which a set of items in a scale measures the same attribute, and by reproducibility, or the extent to which a measure reproduces results on repeated administrations. Questionnaires also are critiqued for validity, or the extent to which survey measures assess what they are supposed to assess, and do not measure what they are not supposed to measure. Validity can be described in terms of content validity, construct validity, and criterion validity. Content validity refers to evidence that the content of the survey is appropriate and relative to the

survey's use. Content validity is determined by expert and lay groups reporting on comprehensiveness of the survey. Construct validity refers to assessment of the patterns of relationships between the measure being validated and other variables related and unrelated to it. The measure is said to have construct validity if it shows a direction and magnitude of relationship that was hypothesized from theory, evidenced by correlation coefficients. Criterion validity refers to the extent to which a measure or survey corresponds to an accurate or previously validated measure or survey of the same concept(s), such as a gold standard.

### **The Parent Feedback Questionnaire<sup>30</sup>**

#### *Aim*

The Parent Feedback Questionnaire was developed to obtain data about parents' perceptions of specific aspects of their hospital experience. The survey is used to monitor neonatal care and to target areas for improvement. The desired outcome is to have parent responses reflect that needs have been met and that they feel satisfied with the hospital experience.

#### *Conceptual Basis*

The survey measures five domains: informational needs, parenting/attachment needs, emotional/spiritual needs, environmental needs, and overall satisfaction. Content was developed through literature review, findings from an expert panel of neonatal staff, and results of parent interview. The questionnaire reads at the 6th-grade level, has been developed into a computerized scannable form, and is translated into Spanish.

#### *Description*

A copy of the survey was not made available in the published report; therefore, instructions and total number of survey items are unknown. The end of the survey allows for narrative comments. The item response category is a five-point Likert scale, a frequency report ranging from never to always and not applicable. Items are worded so that the desired outcome is reflected in a positive response. Examples of two items of informational needs are 1) "I was told the truth about my baby's condition," and 2) "When my baby's condition changed, I was told as soon as possible."

#### *Reliability*

No testing was performed on the reliability of the Parent Feedback Questionnaire. The authors comment that the questionnaire was developed for the purposes of quality improvement and "the methods used in developing the survey were not intended to represent a research study."<sup>30</sup>

#### *Validity*

Content validity was evaluated by literature review, findings from an expert panel of neonatal staff, and results of a convenience sample of parents. The Parent Feedback Questionnaire was revised and

written to a 6th-grade reading level and piloted with a convenience sample of 26 parents. Twenty-three parents reported that the items were important to them. No analyses were performed on the validity of the Spanish translation; no additional validity analyses were performed.

#### *Commentary*

The Parent Feedback Questionnaire was developed to evaluate care and target areas for improvement. The concepts measured in the questionnaire are consistent with those found in the literature and reported by others, thus, it has established content validity. The questionnaire is limited in providing information about parent rating of care delivery. The frequency response scale provides information regarding how often events occur identifying areas to target for quality improvement. What the response scale lacks is parent perception of importance (opinion rating) of the event. No analyses were performed to determine whether the survey is a reliable and valid measure of parent satisfaction. The Parent Feedback Questionnaire is completed at the time of discharge or may be taken home and mailed back. It is unknown if the survey is available.

### **NIPS<sup>26</sup>**

#### *Aim*

The NIPS was developed to distinguish between parents who are satisfied and parents who are dissatisfied with medical neonatal intensive care.

#### *Conceptual Basis*

The authors believed that because it is the parents' perception that determines satisfaction, then parents should define the content of the questionnaire items. Steps were performed to develop the content of the NIPS. The initial phase began with survey item generation developed through literature review and expert opinion of 125 parents and 63 neonatal and pediatric clinicians. This was followed by item reduction in which 60 parents were interviewed and instructed to rate the 154 items on a five-point scale from least important to most important. Items then were rated for importance and frequency of occurrence. Those items identified as positive, most important, and not frequently occurring; and negative, most important, and frequently occurring were included in the NIPS. Through an interview process, the survey then was pretested with 10 parents to ensure clarity and ease of administration. In its final form, the questionnaire measures three domains of parent satisfaction: confidence in quality of care, communication, and attitude or caring/personality. The questionnaire is worded in a manner to "encourage otherwise reluctant respondents to express dissatisfaction with health care."<sup>26</sup>

#### *Description*

The NIPS is a 27-item close-ended questionnaire. The first 17 items are negative in tone and begin with "how often did," and the last 9 questions are positive in tone and begin with "how satisfied were you



with.” The items included were those identified most frequently as sources of dissatisfaction, and those that were rated most important to parents. The item response scale is a seven-point frequency report, ranging from “none of the time” to “all the time.” The questionnaire is administered at time of discharge, and no specific information was given on the process of administration. It was reported that administration took between 15 and 30 minutes. Parents receive a telephone call once they were home to respond to three questions that pertain to the discharge process.

Examples of a few items are Q2) How often did these caregivers present your baby’s condition in a way which was scary or frightening?; Q10) How often did the caregivers fail to inform you about tests or Radiograph results?; and Q20) How satisfied were you with how often the caregivers offered to meet with you in private?

Responses to the items are scored on the seven-point scale, summed, and then interpreted from least satisfied (score of 27) to most satisfied (score of 189).

#### *Reliability*

Reliability testing was evaluated by administering the survey twice to 47 parents within a 1-week period. Three questions were left out of the reliability testing; these were the telephone-administered questions relating to the discharge process. The mean age of parents surveyed was 29.5 years; 77% were women, 68% were married, and 47% completed post-secondary education. Ninety-one percent of their infants had been hospitalized 2 weeks or less. The intraclass correlation between the test–retest administration was 0.71. Although the survey was intended to measure three domains of satisfaction, correlations between the scales ( $R = 0.72$ ) and with the instrument ( $R = 0.87$ ) were high. The authors concluded that the instrument should be used as a unidimensional measure of satisfaction.

#### *Validity*

Content validity was established through literature review, findings from expert clinical and parent panels, and results of pilot testing. The dimensions identified—communication, caring, and confidence/quality of care—are consistent with those reported in the literature. Criterion validity cannot be established, because there is no gold standard for comparative purposes. Construct validity, in this case, predictive validity, was tested by determining how well the instrument would predict parent satisfaction with parent rating of global satisfaction and staff perception of parent rating of global satisfaction. Additional testing for construct validity was conducted by testing the hypothesis that parents who identified errors in medical care would have lower NIPS scores. The NIPS was administered to 832 parents with a mean age of 31 years. Sixty-six percent were women, 81% were married, and 51% had completed postsecondary education. Ninety-one percent had infants hospitalized for <2 weeks. The NIPS had a moderate correlation with parent’s global rating of satisfaction ( $R = 0.61$ ), and weak correlations with caregiver’s

perception of mother’s ( $R = 0.15$ ) and father’s satisfaction ( $R = 0.16$ ). The NIPS had a weak correlation with the parent’s perception of the infant’s health status ( $R = 0.15$ ). Parents who reported medical errors had a mean NIPS score of 127 (standard deviation [SD] = 24.8), compared with parents who did not report errors (mean NIPS score, 141; SD = 26.3;  $P < .001$ ).

#### *Commentary*

The NIPS was tested rigorously to identify constructs of parent satisfaction with neonatal care. The instrument established content validity with these constructs, but it is not comprehensive in measuring the scope of parent satisfaction. The response scale measures frequency of events and does not measure parent reporting or opinion of care. This type of response scale is useful for targeting quality improvement efforts, but provides little information about parent judgments of care. The instrument was tested for reliability and validity in a population of married, educated women of approximately 30 years of age, and can be considered reliable for this population. Reliability was moderate in test–retest (0.71), but intraclass correlation values tend to be lower.<sup>32</sup> The test–retest time of 1 week is beneficial, although recall could be a factor in response. Three items concerning the discharge process were not tested in the test–retest process. Reliability estimates of how well items correlated with their scales were not given, yet it was reported that scales were highly correlated with each other. Thus, the instrument does not have discriminant validity. The instrument has some degree of construct validity supported by the predictive capabilities with global ratings of satisfaction. The NIPS correlated moderately with parent ratings of global satisfaction, and correlated weakly with caregiver perception of parent satisfaction. Items in the NIPS have been worded purposely with a negative tone to measure the “dissatisfied” range of the spectrum. The similarities in the negative wording of the items introduces a response bias,<sup>33</sup> although this was intended. It is important to recognize that measurement of parent satisfaction must include the entire spectrum of parent satisfaction from “dissatisfied” to “satisfied” parents to target efforts at quality improvement and to evaluate caregiving practices. The NIPS may be available for use; inquiries should be directed to the author Mitchell-DiCenso.<sup>26</sup>

### **Inpatient Parent Satisfaction, Children’s Health Care Minneapolis**

#### *Aim*

The Inpatient Parent Satisfaction Questionnaire is a standardized instrument used for all inpatient pediatric and neonatal patients.

#### *Conceptual Basis*

The Inpatient Parent Satisfaction Questionnaire measures overall satisfaction with care, communication, competency, caring, information, timeliness of care, support needs, decision-making and participa-

tion in care, and the hospital environment. No published data were available to critique the questionnaire fully.

#### *Description*

The instrument is a 57-item form that includes both generic and specific measures of satisfaction with multiple skip patterns. Item response categories are open-ended, categoric, dichotomous, evaluative, and endorsement scales. Examples of evaluative rating scales include a three-point scale ranging from "important" to "not at all important," and a four-point "very satisfied to very dissatisfied" rating scale. An example of an endorsement scale is a four-point "strongly agree to strongly disagree" scale. The survey appears to be interviewer-administered. The timing of administration is unknown. Two open-ended items allow for parents to report on their recommendation of changes for the neonatal or pediatric unit and for the hospital. Examples of a few items are Q12) How satisfied are you with Children's Health Care-Minneapolis's entire staff showing concern for your needs? Would you say you are very satisfied, satisfied, dissatisfied, or very dissatisfied? A) The entire staff showing concern for your needs? B) The overall communication of the staff? C) The entire staff viewed your child as a unique person with his/her own unique needs?

#### *Reliability*

No data were made available or could be found to establish reliability of the Inpatient Parent Satisfaction Questionnaire.

#### *Validity*

Content validity can be established by the consistency of concepts represented in the instrument with those in the literature for both pediatric and neonatal parents.

#### *Commentary*

The Inpatient Parent Satisfaction Questionnaire is a standardized instrument developed for the specific purpose of measuring care delivered at one medical center. The survey measures relevant satisfaction concepts of parents with hospitalized children and neonates. The instrument is administered by an interviewer, which increases response rates but can introduce potential bias unless the interviewer administers the form in a standard manner. The form measures expectations of parents and whether their needs were met through rating and reporting scales. It is unknown whether the instrument is available for use.

#### **Picker Institute Inpatient NICU<sup>4</sup>**

##### *Aim*

The Picker Institute Inpatient NICU was developed to measure parent satisfaction with the NICU experience.

#### *Conceptual Basis*

The instrument measures the NICU experience beginning before the infant's admission to the NICU, the admission process, care of the infant after birth, the discharge process, and follow-up care. The instrument also measures access to care, respect for patients' values, coordination of care, information and education, involvement of family and friends, physical comfort, emotional support, transition and continuity of care, and overall satisfaction. No published data were available regarding the Picker Inpatient NICU survey. Some information about the Picker Institute and their survey instruments is available through their Web site.

#### *Description*

The Picker NICU survey is an 81-item instrument with open- and close-ended questions and multiple skip patterns. The instructions state to circle the number that best describes experiences during the child's recent hospital stay. Item response categories include categoric, dichotomous, evaluative rating, and frequency reporting scales. An example of a four-point frequency response scale ranged from "never" to "always." A three-point response scale ranged from "yes, always" to "no." An example of a five-point evaluative rating scale ranged from "excellent" to poor. An open-ended question asks parents to report their suggested changes to the NICU. Dimensions measured on the survey are outlined in bold and include "Admission to the NICU," "Doctors," "Nurses," "NICU staff," "Environment and Visiting policy," "Information and participation in your infant's care," "Leaving the NICU," "Overall impression," and "Your background." Examples of items are Q3) Before your infant's birth, did your discussions with the NICU staff help you to know what to expect after the birth? Q21) Sometimes in the hospital one doctor or nurse will say one thing and another will say something quite different. How often did this happen during your infant's stay in the NICU? Q54) Did someone from the NICU teach you what you needed to know to care for your infant at home?

#### *Reliability*

No published data were found or made available regarding the reliability of this instrument.

#### *Validity*

Content validity can be established by the consistency of the dimensions represented in the instrument with those in the literature. No published data were found or made available regarding validity testing for this instrument.

#### *Commentary*

The strength of this instrument is its ability to measure parent satisfaction along the continuum of the NICU care delivery process. The instrument measures most of the stages in the continuum of care, including the predelivery phase, the admission process, inpatient care, discharge, and follow-up. One

weakness of the instrument is found in the response categories. Many of the item response categories are frequency, which limit interpretation of results. Frequency reporting does not provide information about parent judgments of care, but it is useful for targeting quality improvement efforts. Another limitation with this instrument is the lack of reported or accessible data on reliability and validity of the instrument. This instrument is available for use; inquiries should be directed to the Picker Institute at their Web address (<http://www.picker.org/patient/research.html#survey>).

### NICU-PSF (J.M.C.)

#### *Aim*

The NICU-PSF was developed to make available a comprehensive neonatal parent satisfaction questionnaire that measures parent perceptions of care, targets areas for improvement, and evaluates the quality of care delivered to meet and exceed the needs and expectations of parents and families who receive neonatal care services.

#### *Conceptual Basis*

The NICU-PSF was developed from results of literature review, parent interviews, and parent and neonatal staff reports. A review of adult and pediatric literature was performed to identify recognized concepts of satisfaction. This step involved content analysis of parent interviews conducted at the time of discharge. Fifty-four parents who were surveyed responded to the open-ended question, "What one thing would you change in the intensive care nursery?" A total of 100 statements made by parents were analyzed for content, categorized into dimensions of care, and identified as either positive or negative responses. Content analysis was performed separately by three researchers, and then combined. Three statements required consensus regarding the construct they represented. Seven dimensions of care were identified, including general satisfaction, assurance, continuity, information, proximity, communication, and the NICU. Of responses, 43% were positive, and 57% were negative. The next step included obtaining perceptions of care through a panel group. A 2-day panel meeting of 14 neonatal staff (neonatologists, an ethicist, neonatal nurse practitioners, nurses, and a social worker) and 11 parents was held for an ongoing NICU project. Although the meeting was not held expressly for the identification of content for survey development, core aspects of the neonatal care delivery process were identified. Dimensions of care that arose were anticipation and preparedness, caring, communication, decision-making, environment, information, shared experience, support, and trust. Shared experience was defined as a need to find meaning out of a painful human experience and to have someone to share it with. A preliminary instrument was developed, sent to neonatal staff for expert opinion, revised, and then pretested. The pretest involved mailing the self-administered instrument to 10 selected parents whose infant had been discharged from the intensive care

nursery within 4 weeks. All the parents responded and completed all the questionnaire items. The parents were asked to report on the content of the questions, the readability of the instrument, suggested changes, and their perception of the best time for administration. All reported that the survey addressed the important issues and that the form was readable, but that the format was hard to follow. Most of the parents commented that the NICU experience required some time to process, and they would prefer to be surveyed 4 to 8 weeks after discharge.

#### *Description*

The NICU-PSF is a 62-item instrument with closed- and open-ended questions. The concepts include general satisfaction, continuity, communication, information, preparedness, participation in care, decision-making, support, spiritual needs, proximity, and follow-up care. The final questions ask about delights and disappointments with the hospital experience, suggestions for improvements, and demographics. Instructions at the top of the form ask parents to answer every question by marking the answer as indicated. If a parent is unsure of an answer, they are to mark the best answer possible. Item response categories are rating and reporting scales. An example of rating scales is the five-point scale ranging from "extremely satisfied" to "not at all satisfied" and a five-point rating scale ranging from "excellent" to "poor." Examples of frequency reports include a five-point scale ranging from "all the time" to "none of the time" and a four-point scale ranging from "prepared" to "not nearly prepared." Other response scales are dichotomous and categoric responses. The instrument is self-administered, mailed 3 to 4 weeks after discharge or transfer. Follow-up telephone calls are placed 1 to 2 weeks after the initial mailing, followed by a second telephone call and a second mailing 1 week later.

#### *Reliability*

The NICU-PSF was pilot-tested on families discharged from the hospital from the neonatal intensive care nursery between January 1, 1998, and March 31, 1998. Ninety families were eligible to complete the survey, 89 instruments were mailed (one exclusion because of an infant mortality). The instrument was mailed within 4 weeks from the time of discharge. Six surveys were returned with no forwarding address, and attempts to locate these families were unsuccessful. Final sample size was 83 families, with 50 returning the survey, for a 60% response rate. Parents were Caucasian; 92% percent female; 78% married; and 2% younger than 18 years of age, 25% 18 to 24 years of age, 51% 25 to 34 years of age, and 22% 35 to 44 years of age. Analyses were performed using the Multitrait Analysis Program-Revised.<sup>34</sup> Characteristics reported include frequency distribution, item means, and SD units. The frequency distribution describes whether the response choices were used and whether the distribution is approximately normal. The means within the scale should be approximately equivalent, and the SD



units should be approximately equivalent at 1.0. The responses chosen for the items were mostly favorable for a skewed distribution. The means and SD units for items within a scale were approximately equal, with the exception of a few problematic questions. The internal consistency reliability estimates for the scales met the minimum standard for group comparisons ( $r_{ic} \geq 0.7$ ) for five of the nine scales. Reliability estimates for continuity ( $r_{ic} = 0.67$ ), decision-making ( $r_{ic} = 0.66$ ), support ( $r_{ic} = 0.65$ ), and proximity ( $r_{ic} = 0.52$ ) were below recommended standards. Certain items within scales were problematic, such as one continuity question with an item-scale correlation of 0.26. Item internal consistency is considered substantial if the item correlates  $\geq 0.40$  after correcting for item-scale overlap with its hypothesized scale.<sup>34</sup> Analyses generally supported the hypothesized item-to-scale groupings with some problematic questions. The instrument was not evaluated for test-retest reliability.

#### Validity

Content validity was established through literature review, parent open-ended interviews, parent panel, neonatal staff review, and pilot pretesting. Discriminant validity was tested by determining the correlations of the items to their hypothesized scales and comparing the correlations to other constructs. The decision-making scale was the only scale that achieved 100% scaling success. Continuity of care correlated highly with overall satisfaction and had a high degree of overlap. Discriminant validity was not achieved with the other scales. Criterion validity was not evaluated because of the lack of a gold standard instrument for comparison.

#### Commentary

The content measured in the instrument identified through literature review, parent interviews, and panel meetings was consistent with the content described by others. The instrument was developed and pilot-tested on a small sample of predominantly married women with a lower than desired response rate of 60%. Results would have been stronger with a larger sample size, greater response rate, and more heterogeneous population. The instrument takes advantage of both rating and reporting scales of satisfaction, but the number of different response scales may impact ease and readability of the survey. Meth-

ods typically used to evaluate reliability include test-retest and estimating internal consistency. Most of the scales in the instrument were internally consistent. No test-retest was performed on the instrument. The survey had discriminate validity problems, with some items having higher correlations with other scales. Criterion validity was not established because of a lack of a gold standard for comparison. The NICU-PSF is in preliminary stages of development. Improvements can be made in internal consistency by dropping problematic questions. Additional analyses need to be performed on a large sample to replicate findings. The NICU-PSF is available for use; inquiries should be directed to the author J. M. Conner at the address listed in this publication.

### THE CARE DELIVERY PROCESS

Having identified aspects of neonatal intensive care that are pertinent to parents, it is important to place these dimensions of satisfaction within the framework of the neonatal care delivery process. Using the care delivery process allows providers to recognize "what matters where," to target improvement efforts and to judge the quality of care. It is likely that most, if not all, of the identified constructs are significant to parents throughout the continuum of the care delivery process; however, there may be some concepts that have a greater significance to parents at specific points along the continuum of care. From the studies reviewed, a few constructs identified "where" in the care process parents perceived they were important (Table 4; Fig 3). None of the studies reviewed addressed constructs of parent satisfaction in the predelivery process. At the time of delivery or shortly thereafter, communication and information were identified as significant to some parents.<sup>11</sup> During the acute/critical phase of care, decision-making was recognized as significant.<sup>9</sup> During the discharge and follow-up care phases, education and teaching were highlighted as substantial aspects of care for parents.<sup>29</sup>

It is helpful to conceptualize the parent satisfaction questionnaires within the same framework of the care delivery process (Table 5). The Parent Feedback Questionnaire measured most concepts occurring along the continuum of care. Two questions fall specifically within the acute/critical phase and the discharge phase. The NIPS measures perceptions of care

**TABLE 4.** Dimensions of Neonatal Care Measured Within the Care Delivery Process

Dimension of Neonatal Care	Predelivery	Delivery/ Stabilize	Admission	Transport	Acute/ Critical	Stable/ Improving	Discharge/ Transfer	Follow-up Continuing Care
Assurance					X	X		
Caring			X		X			
Communication		X	X					
Consistent information					X	X		
Education							X	X
Environment					X	X		
Pain management					X			
Participation					X		X	X
Proximity					X	X		
Support								

X indicates dimension of care known to be important at that time in the care delivery process.



**TABLE 5.** Parent Satisfaction Surveys and Where Satisfaction is Measured Along the Care-Delivery Process

	Predelivery	Delivery/ Stabilize	Admission	Transport	Acute/ Critical	Stable/ Improving	Discharge/ Transfer	Follow-up Continuing Care
Parent feedback					X	O	X	
Neonatal index of parent satisfaction					O	O	X	
Inpatient parent satisfaction			X		X		X	
Picker neonatal	X		X		O	O	X	X
Neonatal intensive care unit parent satisfaction					O	O	X	X

X indicates dimension of care measured at that specific point in the continuum.  
O indicates dimension of care measured across the continuum.

across the continuum, with a few measures of the discharge process. Most of the questions on the Inpatient Parent Satisfaction Questionnaire measure care across the continuum. There are questions that measure care during the admission process, the acute/critical phase, and the discharge process. The Picker Inpatient NICU Survey measures care along the continuum and specific points: the predelivery phase, admission, inpatient care, discharge, and follow-up care. Many of the questions on the NICU-PSF measure care along the care delivery process. Two questions measure the discharge process, and three questions measure follow-up care.

### RECOMMENDATIONS

It has been stated that there is a lack of comprehensive information to understand parental needs during a stressful period with a critically ill infant.<sup>24</sup> This has not been found to be the case. Parent perceptions of neonatal care are consistent with parent perceptions of pediatric care, and parents seem to be reporting their needs and expectations for their health care services. The following concepts of parent satisfaction with neonatal care have been identified as important, including accessibility and timeliness of care, assurance, caring, chronic long-term care, communication, competency, continuity, decision-making, follow-up care, information, pain management, participation in care, and support. What is lacking in this evidence is the knowledge of “where” during the care delivery process these aspects of care are most important to parents. Most of these dimensions of care are important across the care continuum, and a few make a difference in specific phases of care. As health care providers, we need to know what the important aspects of health care delivery are as an infant and family moves through the continuum of care. In the first phase of predelivery, one might assume that parents want communication and information most to help prepare for the uncertainties ahead. This may not be the case; parents may only desire the knowledge that their infant will receive immediate and competent attention. Given the lack of knowledge regarding parent’s expectations and needs at each point in the care delivery process, we make the following recommendations for future studies.

#### “Value” of Parent Satisfaction Measurement

Perhaps one of the most important recommendations is to recognize the value in measuring parent

satisfaction with neonatal intensive care services. As providers of health care in a market-driven environment, we must appreciate parents as the consumers of our services and maintain a strong interest in meeting and exceeding their needs and expectations. Patient satisfaction is rapidly becoming a primary measure of the quality of health care plans. Consumers are increasingly judging and choosing their health care plans by patient satisfaction reports. Health care providers are using patient satisfaction reports as a “report card,” providing a marker for improving and tracking care.

#### The Care Delivery Process

We believe that operating within a care delivery process is the right framework for measuring parent satisfaction. We recognize that our “basic” view of the neonatal care delivery process (Fig 3) is not specific and serves only as a general descriptive model of the phases of neonatal care. Efforts need to be devoted to mapping out the important components of parent satisfaction within each phase of the care process, providing a foundation for additional research. Once the conceptual base within the framework is established, a parent satisfaction instrument can be developed. The effort will require qualitative and quantitative research approaches. The remaining sections outline some of the research considerations.

#### Population

Additional research in understanding what matters most and when to parents going through the NICU experience must account for the heterogeneous population. Parents vary in age, gender, socioeconomic status, and marital status, and bring with them cultural and familial beliefs. All these characteristics will influence their expectations and perceptions of neonatal care. Representative sampling is crucial to understanding parent satisfaction for all parents.

#### Content Development

Building on the current conceptual dimensions of parent satisfaction should begin with additional descriptive studies. These efforts can be focused on strengthening the current understanding of these dimensions of care and determine where along the care delivery process they matter. Ideally, a collaborative approach would be taken, with numerous sites performing standardized parent interviews with the goal of describing parent perceptions of care delivery

during each phase of the care process. For example, during the interview process, parents could be queried about the dimensions of care, when they matter, and how they rank them for importance. This approach has the advantage of a large heterogeneous sampling, relatively quick data collection, and attainment of conceptual knowledge for each phase of care. The disadvantage lies in the expense of interviewer training and administration. Other approaches might include focus groups as well as expert parent and neonatal staff panel reporting. Convening a focus group or an expert panel offers the advantages of interested groups meeting and agreeing on the issues, but there will be expenses to consider and the informants may not be representative.

### Questionnaire Development

Survey development is a complex process that requires considerable effort to create a reliable and valid instrument. The current health care environment is encouraging measurement of satisfaction as a means of evaluating the quality of the health care services delivered. With neonatal health care, it has been learned that there are few instruments available to measure parent satisfaction, all which have limitations. Although we do not recommend widespread adoption of these instruments, NICUs need to begin to measure parent satisfaction of the care provided. This can be achieved with selective use of the instruments currently available. An advantage to this approach would be the enhanced understanding of parent needs and expectations and improvement in the instruments. However, this approach is not practical for many medical centers, and other approaches should be considered. The NICU must first establish the purpose for measurement; will it be used to measure parent satisfaction during the entire hospitalization, or will it be used to measure satisfaction with a specific component of health care services (such as the discharge process)? Having established a purpose, some centers might find a simple and practical solution to measuring parent satisfaction by asking parents general open-ended questions about the care or general overall satisfaction questions such as "How satisfied were you with your hospital care?"

Until parent satisfaction questionnaires are documented to be comprehensive, valid, and reliable, these alternative approaches might seem useful. The goal is to develop a comprehensive survey instrument that includes the phases of the care delivery process. We have outlined some important points to consider for designing a survey instrument.

The survey instrument should:

1. Be inexpensive, easy to administer in practice, and place little burden on parents.
2. Be standardized in format, language, mode of administration, data-collection methods, analysis, and reporting.
3. Be internally consistent.
4. Have established content and construct validity.

5. Measure the full range of distribution in parent reporting.
6. Use a combination of rating and reporting response categories.
7. Be analyzed in a standardized manner that allows results to be interpretable for comparative and evaluative purposes.
8. Be reported in a manner that is meaningful and interpretable.
9. Be reported in a manner that targets quality improvement efforts.
10. Be reported in a manner that facilitates evaluative comparison.
11. Be reported in the public domain (for parents and providers).

### CONCLUSION

There is a growing interest in patient satisfaction as an outcome of care and as an indicator of the quality of care. Interest in parent satisfaction with neonatal care is not new, yet the field of parent satisfaction research is limited. Substantial studies need to be conducted to build on the current conceptual knowledge base and to define the constructs within the care delivery process. Few parent satisfaction questionnaires are available, none of which are comprehensive in their measurement of parent satisfaction. These instruments have not been tested and validated fully; furthermore, they measure parent satisfaction in isolation of the care-delivery process. The goal for future studies is to determine what parents' needs and expectations are at each stage in the neonatal continuum of care by developing a comprehensive, valid, and reliable parent satisfaction questionnaire within the context of the health care delivery process.

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