

Impact of Pediatric Critical Illness and Injury on Families: A Systematic Literature Review

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ABSTRACT

OBJECTIVE. We sought to inform decision-making for children and families by describing what is known and remains unknown about the impact of childhood critical illness and injury on families. This report also was designed as a tool for research planning and design so that meaningful studies are performed and duplication is avoided.

DESIGN. After a national scholarship competition and the identification of 3 medical student summer scholars, a literature search was conducted by using the National Library of Medicine and a PubMed keyword search system at the National Institutes of Health.

RESULTS. A total of 115 reports were reviewed and assigned to the 5 following categories characterizing the impact of pediatric critical illness/injury on families: stressors, needs, specific domains (psychological, physical, social), coping, and interventions. The reports reviewed indicate that pediatric critical illness and injury is stressful for the entire family. The effects on parents, siblings, and marital cohesion were variably described. Needs of family members (eg, rest, nutrition, communication) were identified as being unmet in many studies. Permanent impact on siblings and marital relationships has been considered detrimental, but these conclusions are not adequately quantified in presently available studies. Reviewed reports minimally investigated cultural diversity, effects on fathers versus mothers, siblings, socioeconomic status, and financial burden. Studies were often anecdotal and included small sample sizes. Methodologic limitations were numerous and varied and seriously narrowed the significance of the studies we reviewed. The reports that we evaluated were largely limited to those of English-speaking families, white people, and married mothers.

CONCLUSIONS. Future research should use more rigorous methods in the measurement of impact of childhood critical illness and injury on families. Families of critically ill and injured children would benefit from the practitioners of pediatric critical care acquiring enhanced knowledge and sensitivity about family communication and dynamics.

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Key Words

critically ill children, siblings, injury, family impact, PICU

Abbreviations

NIH—National Institutes of Health
PSS:PICU—Parental Stressor Scale: Pediatric Intensive Care Unit
PTSD—posttraumatic stress disorder

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PICUs FOR CRITICALLY ill and injured children are expanding in number and size.¹ A 1998 estimate that 200 children per 100 000 in a population will require intensive care annually² is probably conservative. Pediatric critical care services support children admitted with life-threatening medical conditions, as well as postoperatively after cardiovascular, orthopedic, neurosurgical, microvascular, plastic, and reconstructive procedures. Innovations in pediatric surgery, hematology/oncology, and state-of-the-art advanced life support techniques have expanded treatment options for critically ill infants and children. Mortality rates in childhood critical illness and injury have plummeted, and death rates in PICUs are uniformly low even for tertiary units at 1.5% to 8%³ (see Appendix 1).

This targeted change in mortality was described in the *Healthy People 2010*⁴ agenda as the reduction in deaths of infants, children, and adolescents from all causes. Aggressive programs of education and training have been implemented to prevent deaths resulting from violence, drowning, poisonings, and trauma. Basic and advanced professional training in the techniques of life support has been widely instituted with the goal of reducing child deaths resulting from shock of traumatic and septic origin, head injury, and cardiorespiratory failure.

BACKGROUND

Young people (from birth to adulthood) with special health care needs represent a large segment of the population in our PICUs. One recent study of PICU demographics reported that 45% of children admitted emergently had preexisting special health care needs, and 3% were already technology dependent.⁵ In the remaining 55% of urgent admissions in previously healthy children, one would expect that many will have special health care needs and/or be technology dependent by the time of PICU discharge. In addition, when one considers the postoperative population in the PICU, it is evident that the majority of children in PICUs are characterized by the following long-term special health care needs: chronic illness, technology dependence, and developmental disability.^{3,6}

Survival is no longer an adequate measure of pediatric critical care practice, because mortality is a rare event. Morbidity and disability in the rapidly growing cohort of survivors remain poorly quantified. The experience of the death of a child, a common event in much of the world, has become rare in the United States. Indeed, Newachek et al⁷ estimate that most pediatricians will have 3 or fewer children die during a practicing lifetime. These same authors report that general pediatricians provide inpatient care for only small numbers of children annually.

According to Centers for Disease Control and Prevention statistics, 45 054 children and young adults died at between 1 and 24 years of age in the United States in

2002 (see Appendix 1, drawn from Centers for Disease Control and Prevention data), the majority as a result of accidents, homicide, or suicide. A smaller number died as a result of medically intensive illnesses such as cancer (7.1%), congenital anomalies (3.2%), and heart disease (3.2%).⁸ Approximately 5000 children die each year as a result of life-limiting chronic disorders such as neurodegenerative diseases, cystic fibrosis, muscular dystrophy, and HIV-1.⁹ The slow downward spiral that precedes the final admission may exhaust family finances, relationships, and coping abilities.

The impact on siblings and marital relationships is not described in large, detailed studies, but it is widely considered to be substantial and detrimental.¹⁰⁻¹² This is a subject of considerable interest in the pediatric palliative care literature.¹³ Substantially fewer studies are found about the impact of the disability and chronic illness on families that more often characterize child health after PICU discharge. To understand the impact on families of childhood critical illness and injury we performed a systematic literature review.

Family structures are increasingly recognized as heterogeneous, thereby adding a varying dimension to the impact of critical illness and injury. Examples include single-parent households, "blend" families created by new marriages and/or domestic partnerships, multigenerational families, gay/lesbian caregivers, foster and adoptive homes, and transgenerational models, in which grandparents, aunts, uncles, and older siblings act as primary caregivers. Cultural diversity and differences in stability of family units over time are to be expected.¹⁴ For instance, families may be thousands of miles away from their traditional support systems and spiritual resources because of political and social upheaval and immigration.¹⁵

An ICU stay is characteristically volatile for critically ill children, caregivers, and parents; dramatic swings in illness trajectory toward both deterioration and recovery are common. The impact of these events on family dynamics, stress, and coping has been the subject of some reports, especially in the nursing and sociologic literature. Although most studies are small and many are anecdotal, a common theme emerges: critical illness in childhood is a source of distress not just for the child in the PICU but for the entire family.^{16,17}

SIGNIFICANCE

Commonly, primary care pediatricians supervise the care of children with multisystem residual disability, activity limitations, and technology dependence.¹⁸ Children with complex regimens of care and multiorgan system disability are returned to the care of their families and medical home providers after an ICU stay, too often with alarmingly little provision for support.¹⁹ This integration of children with disability and special health care needs into general pediatric practice is expanding as the

population of disabled children grows. Using a systematic literature review, we sought to inform decision-making for this growing population of children and families with special health care needs after childhood critical illness or injury. We also sought to describe research gaps in which application of scientific and analytic methods might inform and ultimately improve care of children with complex residual special needs.

The systematic literature review was conceptually organized around the elucidation of stressors experienced by families, the needs described by families, and the overall family impact of childhood critical illness and injury. We found published reports describing the impact on these families in the psychological, physical health, and social arenas of their lives. In addition, we sought to review and report on the literature that describes family coping under these circumstances, especially where focused, professional interventions have been demonstrated to ameliorate untoward family impact.

METHODS

A national competition was conducted in the spring of 2005 to identify scholars who would evaluate the literature about the family impact of childhood critical illness and injury. Every Association of American Medical Colleges–accredited academic medical institution within the United States was contacted via its dean of students/student affairs. The competition yielded 3 summer scholars, Ms de Almeida, Ms Ly, and Ms Shudy (medical students who began their scholarship in the summer between their first and second years of studies), at the National Institutes of Health (NIH), Office of Rare Diseases, and the National Institute of Child Health and Human Development (National Center for Medical Rehabilitation Research, Program in Pediatric Critical Care and Rehabilitation Research) in Bethesda, Maryland.

The literature search was conducted by using the National Library of Medicine, accessed through the NIH library system. PubMed, a computerized database containing articles published between 1966 and 2005, was the primary search engine used. Citations retrieved were relevant to family adjustment and pediatric critical care. A spectrum of keywords was entered in different combinations and included “child,” “illness,” “impact,” “families,” “chronic,” “critical,” “experience,” “siblings,” “effects,” “pediatric,” “care,” “parents,” “PICU,” “teenagers,” “disability,” and “trauma.” Articles relevant to 5 areas of family impact were identified: stressors, needs, impact, coping, and interventions. Reports were reviewed and categorized by the scholars. We excluded literature about the effect of child death in isolation from critical illness and injury, because there are many extensive reviews of this subject.^{13,20–23} Additional perspective on the dynamics of health care workers and critically ill children and their families was gained during biweekly

rounds at the Children’s National Medical Center PICU in Washington, DC, a 24-bed unit with a census of >1400 patients per year.

The literature was reviewed and summarized in tabular form by the scholars. Supervision was provided by a pediatric intensivist (Dr Nicholson). Additional knowledge was gained through interaction with a pediatric pulmonologist who serves as medical director of a multidisciplinary service for children with special health care needs (Dr Landon).

RESULTS: SYSTEMATIC LITERATURE REVIEW

Stressors Identified in Families of Critically Ill Children

The admission of a critically ill child to the PICU imposes immense burdens on parents, siblings, and other family members.^{24,25} We reviewed 13 studies that specifically addressed stressors that negatively affected the families of critically ill children (Table 1). The milieu of the ICU, the presence of numbers of desperately sick children, their families and caretakers, and the intensity of the PICU personnel are understandably alien to shocked and grieving parents. The continual presence of bright lights (without respect to diurnal cycles) and the unceasing vigilance of the PICU staff present an intimidating environment.^{26,27} To inform pediatric critical care practice, several investigators sought to describe specific stressors and subsequently develop appropriate interventions.²⁸

Kasper and Nyamathi defined stress as “circumstances that place physical or psychological demands on the individual and the overall emotional reactions experienced by the individual or family.”²⁹ Miles and Carter²⁴ classified the identified sources of stress experienced by parents of children in a PICU as situational, personal, and environmental; they developed the Parental Stressor Scale: Pediatric Intensive Care Unit (PSS:PICU) instrument.²⁴ This clinical assessment tool evaluates stressors as perceived by parents³⁰ and has prompted subsequent analytic studies of PICU family stress.^{26,31–37} As shown in Table 1, studies using the PSS:PICU indicate that the most severe parental stress is role alteration.^{25,26,37} This is understood as the sense of helplessness in parents who are accustomed to control in providing safety and advocacy.²⁷ Other identified stressors include alterations in the child’s appearance, machine alarm sounds, nursing procedures, and communication difficulties with PICU staff.^{24,38}

Most reports of parental stress after emergent PICU admission indicate that early anxiety levels are elevated to near panic. These levels subsequently decline and stabilize.^{39,40} A positive correlation between the number of invasive procedures and the level of parental anxiety was observed. Because such procedures correlate with acuity, this is an expected finding.³⁹

Parental sensitivity to environmental stimuli in the PICU becomes less acute over time, whereas dimensions

TABLE 1 Systematic Literature Review: Stress Factors and Outcomes in Pediatric Critical Illness

Author (Year)	Design	Sample	PICU Stressors	Stress Measure	Stress Symptoms and Findings
Balluffi et al ³⁸ (2004)	Prospective	272 PICU parents	Child's physical appearance; uncertain outcome	Acute Stress Disorder Scale; PTSD Checklist	Traumatic stress after discharge; hyperarousal
Board and Ryan-Wenger ⁷¹ (2002)	Prospective, comparative	31 PICU mothers; 32 GCU mothers; 32 mothers of nonhospitalized children	Procedures; alteration in parent role	PSS; PICU; SCL-90-R; FAM III; FILE	PICU mothers were more stressed than the other mothers
Board ⁷¹ (2004)	Prospective, comparative	15 PICU fathers; 10 pediatric ward fathers	Tubes and needles in child; helplessness; injections	PSS; PICU	PICU fathers were more stressed than the other fathers
Board and Ryan-Wenger ²² (2003)	Comparative	31 PICU mothers; 32 pediatric ward mothers	Monitor alarms; tubes and needles in child; various people speaking	PSS; PICU	PICU mothers exhibited more stress symptoms than other mothers
Eberly et al ²⁶ (1985)	Comparative	233 PICU parents, planned admissions; 262 PICU parents, unplanned admissions	Parental role alteration; child's appearance, behavior, and emotions	PSS; PICU	Loss of parent-child relationship was more stressful than physical stimuli
Graves and Ware ⁴² (1990)	Comparative	36 mothers; 14 fathers; 50 staff	Uncertain length of PICU stay; absence during doctor visits; other patients crying	Inventory with 5-point scale	Fathers were less stressed than mothers; parental stress not always accurately perceived by staff
Haines et al ³⁶ (1995)	Comparative	54 PICU parents of intubated children; 17 PICU parents of nonintubated children	Painful procedures; child's behaviors and emotions	Modified PSS; PICU	Parents of intubated children were stressed more by painful procedures; parents of nonintubated children were stressed more by child's behavior and emotions
Huckabay and Tilem-Kessler ²⁹ (1999)	Qualitative	96 PICU parents	Unhealthy or dying child; loss of parental role	MAACL; SSA	More procedures increased stress; no stress difference between fathers and mothers
Johnson et al ³³ (1988)	Comparative	29 PICU mothers; 12 PICU fathers	Child's behavior and emotions; parental role alterations; staff behavior	PSS; PICU (5-point Likert scale); STAI	Fathers were stressed more by sights and sounds than mothers
Landolt et al ⁴⁴ (2003)	Comparative	355 PICU parents	PTSD and PDS predictors were high SES and long hospital duration	PDS (4-point Likert scale)	Family cohesion positively correlated to patient quality of life and adjustment
Long ³⁷ (2003)	Review	Cohabiting parents	Distance from hospital; financial burden; parental role alteration	Not specified	Interruption of usual home, work, and leisure activities disrupted families
Miles and Carter ²⁴ (1982)	Qualitative	10 PICU parents; 11 PICU nurses	Child's behavior and emotions; parental role alterations	Observation; interview	Preparation of parents for the PICU experienced reduced stress
Miles and Mathes ³⁴ (1991)	Qualitative	28 PICU parents	Child's behavior and emotions; parental role alterations	PSS; PICU (5-point Likert scale); PPO; interview	Parents were more prepared for physical environment than emotional dynamics
Simon ⁴⁵ (1993)	Descriptive	21 PICU brothers; 24 PICU sisters	Changes in parent behavior; substitute caregiver; too much time in hospital	CD; H; 2-pile card sort	No significant correlations between age, gender, and stress
Youngblut and Jay ⁴⁰ (1991)	Quantitative	17 parents	Child's pain; possibility of child's death	Parental Concerns Scale; interview	Total concerns decreased over time

CD-H indicates Child Drawing Hospital; FAM III, Family Assessment Measure III; FILE, Family Inventory of Life Events and Changes; GCU, general care unit; MAACL, Multiple Affect Adjective Check List; PDS, Posttraumatic Diagnostic Scale; PPO, Parent Preparation Questionnaire; SCL-90-R, Symptom Checklist-90 Revised; SES, socioeconomic status; SSA, Spielberger's State Anxiety; STAI, State-Trait Anxiety Inventory.

TABLE 2 Systematic Literature Review: Needs of Families of Children in PICUs

Author	Design	Sample	Needs	Findings
Farrell ⁵⁴ (1989)	Qualitative	Data from 18 studies	Contact with child; nearby resting place	Abdication as primary caregiver unfamiliar and distressing
Farrell and Frost ¹¹⁰ (1992)	Qualitative	27 parents of children having heart surgery	Know what is wrong with child; informed of changes	Parents needed accurate information and anxiety relief
Kasper and Nyamathi ²⁹ (1988)	Qualitative	15 PICU parents	Contact with child; accurate information; nearby resting place	Parental needs categorized as psychological (58%), physical (27%), and social (15%)
Kirschbaum ⁵⁵ (1990)	Qualitative	41 PICU parents	Feeling of hope; assurance of best care; maintaining caregiver role	Parents need to be recognized as important to the child's recovery
Kleiber et al ⁴⁹ (1995)	Qualitative, exploratory	14 PICU parents; 12 PICU siblings	Family cohesion; hospital visits; information	50% of parents withheld information from child's siblings
Scott ⁵³ (1998)	Descriptive, comparative	21 PICU primary caregivers; 17 PICU nurses	Visit child often; assurance of best care; honest answers	Differences existed between the primary caregivers' and nurses' perceptions of specific family needs

such as staff communication and behavior become stronger determinants of parental stress.^{26,37,39} Parental needs may change as novel equipment and procedures become more familiar. At some point then, parents focus on the decision-making process including interaction with the hospital staff and learning about the child's care.²⁷

In describing parental stress levels, researchers have reported that parents who experienced an unplanned PICU admission had higher mean scores on all stress dimensions than those whose children were admitted electively.²⁶ Mothers regarded the PICU experience as more stressful and scored higher stress levels (on PSS: PICU measures) than fathers in one study³¹ and were reported as more stressed than fathers in another study.⁴¹ However, other authors have found that mothers and fathers seem to experience the same level of stress elicited by different stimuli.⁴² Other researchers have found no significant difference in stress levels between mothers and fathers.^{35,39,43} In general, there were disproportionately small numbers of participating fathers in the study samples.^{42,43}

Two studies concluded that parents' and PICU nurses' perspectives on parental stressors have significant discrepancies. Parents reported feeling more stressed by their child's behavioral and emotional response, but nurses expressed greater concern about staff communication.^{33,43} These differences between staff and parental perception of characteristic stressors were the subject of only a few reports.

Landolt et al⁴⁴ reported that stress was positively correlated with higher socioeconomic class. Loss of parental control in relatively advantaged parents may produce more acute stress-level elevation, but this remains unproven. Another group reported that parents of intu-

bated children were found to be more distressed by painful procedures, as compared with parents of nonintubated children, who were more distressed by the behavioral and emotional responses of their children. This result was despite the underlying difference in sedation and consciousness.³⁶

Few studies have investigated stress in healthy children when a sibling is hospitalized with critical illness or injury. Those we reviewed concluded that the main sources of stress in siblings were changes in parental behavior and care by a substitute caregiver. Reviewed reports indicate that there is no significant correlation between the age or gender of siblings and level of stress.^{45,46} The authors of one study found higher stress levels in siblings who visited the PICU daily, implying that repetitive contact with distressing content may be more anxiety-producing.⁴⁵ Older siblings in households with a child in the PICU may assume parental responsibilities,⁴⁷ and the effect on their development remains understudied.⁴⁵ In other reports, concentration of the single caregiver on the critically ill child resulted in age-inappropriate adult responsibilities for siblings and relative neglect of their needs.^{46,48}

Kleiber et al⁴⁹ reported that the needs of siblings of critically ill children revolve around the maintenance of a familiar lifestyle. Needs for siblings included family cohesion, distraction from the immediate crisis, hospital visitation, and developmentally appropriate information. Assessment of sibling developmental levels ideally should provide the platform for information and level of detail about a critically ill brother or sister. Because the parents are distracted, availability of such assessment and communication for siblings remains problematic. Symptoms of depression in siblings have been reported as a prominent psychological finding.⁴⁸ Worry and fear

TABLE 3 Systematic Literature Review: Psychological Impact on Families of Children With Critical Illness

Author	Design	Sample	Outcome Measure	Impact
Carnevale ⁵⁰ (1999)	Qualitative, prospective, longitudinal	10 PICU families	Interview	Parents felt guilty, excited, discouraged, and exhausted during hospitalization; siblings felt isolated, unimportant, and resentful
Chien et al ⁵⁵ (2003)	Prospective	29 families of children treated for brain tumor	Quality-of-life measure	Parents were more negatively affected psychologically than other populations
Hall ⁵⁶ (2004)	Qualitative, exploratory, retrospective	7 grandmothers of critically ill children	Interview	Grandmothers were concerned with being supportive
Hall ⁵⁷ (2004)	Qualitative, exploratory, retrospective	7 grandfathers of critically ill children	Interview	Grandfathers were concerned with being supportive as both a father and grandfather
Johnson et al ⁵⁹ (1995)	Qualitative, exploratory, prospective	52 ICU family members	Iowa ICU Family Scale	Family unit experienced changes in emotions, routine, and increased responsibilities
Katz ⁷² (2002)	Prospective, comparative	40 children with LT illnesses; 40 children with NLT illnesses	4 measures of sociodemographics, illness, impact, and coping	Parents of children with LT illnesses were given more emotional support than those with NLT illnesses
LaMontagne et al ⁵⁸ (1994)	Quantitative, comparative	22 parents of critically ill children	5 measures for catecholamines, coping, anxiety, parent activities, and cognition	Parents of younger children exhibited higher dopamine-response levels and anxiety
Leidy et al ⁷² (2005)	Quantitative, prospective	46 caregivers/children with RSV; 45 caregiver/control children	9 measures for health, stress, and adaptability	Caregivers of children with RSV reported higher anxiety than those of children without RSV
McMahon et al ⁴⁸ (2001)	Prospective, cross-sectional	12 siblings of children with severe TBI; 11 controls	4 measures for child behavior and mental status	Functional outcome of patient at discharge was positively correlated with sibling self-concept
Montgomery et al ¹⁰ (2002)	Qualitative, prospective, longitudinal	32 families of children with TBI	Survey	Family dynamics were negatively affected; siblings exhibited increased fears and withdrawal from injured child
Noyes ⁶⁰ (1999)	Qualitative, exploratory	10 PICU mothers	Interview	Mothers experienced shock crisis; valued information and individualized, competent care
Rees et al ⁷⁴ (2004)	Retrospective, comparative	35 PICU families; 33 non-PICU families	4 measures of impact of event, health, depression, and anxiety	Positive correlation between PTSD in parents and child's symptoms; admission length, and perceived illness threat
Shears et al ⁶³ (2005)	Prospective	78 PICU or pediatric ward families	3 measures for impact of event and general health	Child psychiatric symptoms and parental PTSD symptoms were positively correlated to length of stay
Sparacino et al ¹² (1997)	Qualitative, pilot, prospective	8 parents of young adults with CHD	Interview	Siblings felt neglect and rivalry
Stancin et al ⁶⁵ (2001)	Concurrent, prospective, longitudinal	57 children with serious fractures and their caregivers	5 measures for sociodemographics, injury severity, and family burden	Family unit experienced increased stress, social distress, and adverse psychological effects
Tomlinson et al ⁶⁶ (1995)	Prospective, longitudinal, descriptive	20 PICU mothers	3 health measures	Mothers displayed a significant decline in mental health if child had potential chronic deficit
Wade et al ⁸⁰ (1998)	Prospective, longitudinal, comparative	109 children with TBI; 80 children with orthopedic injury	6 measures for family impact and adjustment	High levels of family burden, parental distress, and comorbidity associated with TBI
Youngblut and Shiao ⁶⁹ (1992)	Prospective, correlational, repeated (4X)	29 PICU parents; 16 PICU children	PRISM; PCS; PSS-PICU	Parents' reactions to PICU, concerns, and stressors not significantly correlated to illness severity

CHD indicates congenital heart disease; LT, life-threatening; NLT, non-life-threatening; PCS, pediatric cardiothoracic surgery; PRISM, Pediatric Risk of Mortality; RSV, respiratory syncytial virus; TBI, traumatic brain injury.

TABLE 4 Systematic Literature Review: Physical Health Impact on Family Members of Children With Critical Illness

Author	Design	Sample	Outcome Measure	Impact
Carnevale ⁵⁰ (1999)	Qualitative, prospective, longitudinal	10 families of critically ill children	Interview	Parents were physically and emotionally fatigued from experience
Chien et al ⁷⁵ (2003)	Prospective	29 families of children treated for brain tumors	Measure for quality of life	Parents had significantly lower quality of life and physical health compared to healthy adults
Johnson et al ⁵⁹ (1995)	Qualitative, prospective, exploratory	52 ICU family members	Iowa ICU Family Scale	Family unit changed routine
Leidy et al ⁷² (2005)	Quantitative, prospective	46 caregivers of children with RSV; 45 caregivers of control children	9 measures for health, stress, and adaptability	Family unit and parents experienced a decline in health that lasted 60 d beyond discharge
Noyes ⁶⁰ (1999)	Qualitative, exploratory	10 PICU mothers	Interview	Mothers had physical symptoms after admission
Rees et al ⁷⁴ (2004)	Retrospective, comparative	35 PICU families; 33 non-PICU families	4 measures of event impact, health, depression, and anxiety	Parents did not have difference in residual physical health after discharge
Tomlinson et al ⁶⁷ (1995)	Prospective, longitudinal	20 PICU mothers	3 measures for medical outcome, health, and physiological stability	Family unit experienced new health problems postdischarge

RSV indicates respiratory syncytial virus.

about the sibling's own health and safety and detachment from the critically ill/injured child are typical findings.¹⁰ Feelings of guilt, isolation, and relative unimportance in the family are reported as well. Overt resentment or rivalry toward the ill child who is receiving more parental and social attention is also common.^{12,50,51}

Needs of Families of Critically Ill Children

Family-member reactions include anguish, helplessness, and aggravation. If unresolved, such responses may adversely affect the well-being of the entire family.⁵² Most pediatric critical care professionals feel an obligation to minimize parental stress and preserve family well-being. Such well-intentioned practice patterns must be based on accurate identification of parental needs.²⁵ We have summarized 6 studies that identified the needs of families of critically ill children (Table 2).

When uncertainty about the child's prognosis persists, parental stress from fatigue, poor nutrition, and anxiety can escalate to crisis levels.^{27,53} Fundamental physiologic needs are often overlooked; in addition, parents themselves may be unlikely to ask for fresh water, food, and sleeping facilities.²⁷ Needs commonly identified by parents include seeing the child frequently, feeling that there is hope, knowing that the PICU personnel care about the child, having a waiting area near the unit, and feeling that questions are answered honestly.^{27,53–55} Mi-Kuen and Kai-kwong⁵⁶ categorized these needs into 4 categories: proximity, information, support/encouragement, and comfort. Other studies have identified parental needs that fit readily into these categories.^{29,53,54,57}

Kasper and Nyamathi²⁹ found that the majority of parent-identified needs were psychological (58%), and other studies confirm this.^{53,55} One study reported that

parents (mostly mothers) identified the need to be prepared for the ICU.⁵⁸ Commonly, PICU admission, critical illness, acute deterioration, and critical trauma are not anticipated, and advance preparation is not an option.

Impact on Families of Critically Ill Children

Studies of the specific impacts on families were evaluated by methodology, time/follow-up axis, and principal findings. These 27 studies are summarized in Tables 3, 4, and 5. Many of these reports^{10,48,59–70} specified impacts on families of children during critical illness and after discharge and used similar outcome measures. These impacts were identified by using the PSS:PICU^{31,69–72} and Family Adaptability and Cohesion Evaluation Scale III.^{61,64,68,72}

Nine articles examined family impact postdischarge.* The authors of several cohort-comparison studies attempted to elucidate the difference between family impact in life-threatening and non-life-threatening disease states.^{31,41,71,73,74} Sample sizes varied markedly (range: 7–189 families), and many were anecdotal. Most studies described findings in cohorts that were largely white and excluded non-English-speaking families. This limitation is a crucial deficit and vital to note when planning future research. In addition, most family-impact data have been obtained from mothers,^{12,63,67,69,71,74,75} although one study was conducted solely with fathers.³¹ A substantial number of studies have focused on children who were in the PICU for the first time.^{58,60,67,69–71,74,76,77} Eight studies compared families of children who were admitted emergently to the PICU to those admitted who were admitted nonurgently.^{31,50,60,61,69,70,76,77}

We reviewed 18 articles that described the psycholog-

*Refs 14, 31, 41, 62, 65, 67, 69, 70, and 72.

TABLE 5 Systematic Literature Review: Social Impact of Family Members of Children With Critical Illness

Author	Design	Sample	Outcome Measure	Impact
Board and Ryan-Wenger ⁷¹ (2002)	Prospective, comparative	31 PICU mothers; 32 GCU mothers; 32 nonhospitalized mothers	PSS; PICU; SCL-90-R; FAM III; FILE; PRISM	Increased PICU maternal stress correlated with worsened perception of family functioning postdischarge
Camevale ⁶⁹ (1999)	Qualitative, prospective, longitudinal	10 families of critically ill children	Interview	Family unit: shift in strength of relationships; parents: devote first days to child and put all else aside
Chien et al ⁷⁵ (2003)	Prospective	29 families of children treated for brain tumor	Quality-of-life measure	Better outcome by caregivers related to better outcome of child's health
Johnson et al ⁶⁹ (1995)	Qualitative, prospective, exploratory	52 ICU family members	Iowa ICU Family Scale	Family members: experienced an increased sense of responsibility, emotional, and routine changes
Ledy et al ⁷² (2005)	Quantitative, prospective	46 caregivers of children with RSV; 45 caregivers of control children	9 measures for health, stress, and adaptability	Caregivers of children with RSV: poor family functioning, cohesion, and adaptability lasting beyond 60 d postdischarge
McMahon et al ⁶⁸ (2001)	Prospective, cross-sectional	12 siblings of children with severe TBI; 11 case controls	4 measures for child behavior and mental status	Siblings: no significant correlation between functional outcome of patient and depression symptoms
Montgomery et al ¹⁰ (2002)	Qualitative, prospective, longitudinal	32 families of children with TBI	Survey	Family unit: negative impact on family dynamics; relationships, finances, and employment; siblings: behavioral, school, and peer difficulties
Philichi ⁶¹ (1989)	Prospective	50 PICU parents	FACES-III; F-COPES	Family unit: mostly balanced in adaptability and cohesion; parents: no difference in cohesion
Rivara et al ⁶² (1996)	Prospective	81 families of children with TBI	7 measures for family health, relationships, and life events	Family unit: preinjury functioning best predictor of family functioning outcome at 3 y
Shields and Tanner ⁶⁴ (2004)	Qualitative, observational	2 pediatric teaching hospitals	Measure of food, travel, and parking costs	Parents: parking, meals, driving distance, and work absence inflict extra financial burden and communication; parents: marital problems and divorce
Sparacino et al ⁷² (1997)	Qualitative, exploratory, prospective	8 parents of young adults with CHD	Interview	Family unit: social changes in family activity and communication; parents: marital problems and divorce
Stancin et al ⁶⁵ (2001)	Concurrent, prospective, longitudinal	57 children with serious fractures and their caregivers	5 measures for SES, injury severity, and burden	Family unit: increased family burden and adverse effects in children with lower extremity injury compared to upper extremity injury
Tak and McCubbin ⁶⁶ (2002)	Secondary analysis of longitudinal study	92 families of children with CHD	FILE: Self-report Personal Resources Questionnaire; CHIP	Parents: direct effect between family stress and perceived social support and coping social functioning
Tomlinson et al ⁶⁷ (1995)	Prospective, longitudinal	20 PICU mothers	3 measures for health of patients and families	Family unit: no major interruptions in role or social functioning
Wade et al ⁶⁰ (1998)	Prospective, longitudinal, comparative	53 children, severe TBI; 56 children, moderate TBI; 80 children, orthopedic injury	6 measures for family impact and adjustment	Family unit: family dysfunction significantly higher in severe TBI group; parents: no significant difference in marital adjustment
Winthrop et al ⁶⁸ (2005)	Prospective, longitudinal, descriptive	162 families of children with serious trauma	CHQ Parent Form 28; FIM; IOF	Family unit: impact on economics and family functioning greatest 1 mo postinjury; lower child psychosocial/physical scores correlated with greater social impact
Youngblut and Lauzon ⁷¹ (1995)	Randomized, comparative, retrospective	27 PICU families; 25 GCU families	FACES-III; FFFS; PRISM	Family unit: location in hospital, length of stay, and illness severity are negative impact components
Youngblut and Shiao ⁷⁰ (1993)	Prospective, exploratory, repeated (2X)	9 PICU parents	6 measures for stress, behavior, family illness, and adaptability	Family unit: cohesion decreased postdischarge

CHD indicates congenital heart disease; CHIP, Coping Health Inventory for Parents; CHQ, Child Health Questionnaire; F-COPES, Family Crisis Oriented Personal Evaluation Scale; FACES-III, Family Adaptability and Cohesion Evaluation Scale III; FAM III, Family Assessment Measure III; FFFS, Feetham Family Functioning Survey; FILE, Family Inventory of Life Events and Changes; FIM, Functional Independence Measure; GCU, general care unit; IOF, Impact on Family Scale; PRISM, Pediatric Risk of Mortality; RSV, respiratory syncytial virus; SES, socioeconomic status; SCL-90-R, Symptom Checklist-90 Revised; TBI, traumatic brain injury.

ical impact on families of children with critical illness and injury (Table 3). Six articles focused exclusively on the effects on mothers.^{31,50,60,66,67,73} Shears et al⁶³ reported that a higher percentage of mothers than fathers had symptoms of psychiatric disorder and/or posttraumatic stress disorder (PTSD) at admission and after discharge of the child from the PICU. Tomlinson et al⁶⁷ noted increased psychological distress and decreased well-being in mothers when critically ill children were diagnosed with an illness/injury that would have a chronic component, as compared with mothers of those children with time-limited illness/injury. Additional research is needed to quantify the increasing amount of familial psychological stress generated by the drastic decrease in PICU mortality rates and increasing survival rates of children with disabilities.

Parents of children with life-threatening illnesses received support more often from health care personnel than did parents of children with chronic illnesses according to one report.⁷³ Thus, acuity of the disease and its stage in evolution toward chronicity may influence the amount and types of support resources available to parents. This finding is important, because other data (see description of stressors above) imply that maternal stress levels increase when incomplete recovery or chronic diseases are likely outcomes.³

We reviewed 7 studies that reported physical health impact on families (Table 4). Findings included deteriorating physical health in parents and caregivers compared with adult peers.^{50,75,78,79} Mothers and fathers both were reported to have similar physical reactions to critical illness or injury in their children: numbness, malaise (as in impending illness), fatigue, headaches, and irritability.^{31,60} Deleterious impacts on family health behaviors such as sleep and meal patterns were reported along with infections and stress-related symptoms such as headache, low energy, and anxiety.[†]

Eighteen studies that described social impact on families of critically ill children are reviewed in Table 5. Categories of social effects were in several areas: economics, family roles, function, cohesion, and interpersonal relationships. Carnevale⁵⁰ found that attachment strength increased shortly after the PICU admission while, at the same time, relationship changes were more profound as illness severity increased. Several others reported this direct relationship between severity of illness and negative family social impact.^{12,42,68,80} A crucial area of study is marital conflict and divorce.^{10,12} Negative impact on marital and domestic-partner relationships has been described elsewhere.¹¹ In contrast, Philichi⁶¹ found no difference in family cohesion, and this finding was confirmed by another study.⁶⁷ The commonly expected financial stress, employment loss, and overall negative socioeconomic impact on families with a criti-

cally ill child were documented by only one study in our review.⁶⁸

Of course, family functioning, adaptability, and resilience are affected by many factors including baseline function before critical illness/injury.^{51,70} Two studies reported no significant change in social function in families of children with critical illnesses.^{61,67} Mothers tended to see the family as dysfunctional, with decreased cohesion postdischarge,^{70,71} but were content with overall family function. Maternal stress was reported as directly related to illness severity, duration of PICU stay, distance of the unit from family home, and length of mechanical ventilation.^{42,70} It seems likely that maternal stress levels are indicators of overall family social impact, but this remains to be clearly demonstrated.⁶⁷

Family Coping in Pediatric Critical Illness

“Coping” can be defined as the behavioral and cognitive efforts used to manage internal and/or external stressful demands that outweigh an individual’s immediately available resources.⁸¹ Thirteen studies have evaluated family coping behaviors in the context of critical childhood illness/injury (Table 6). Melnyk⁸² described 2 primary types of coping strategies: emotion-focused coping, characterized by positive reappraisal, self-control, and distancing, and problem-focused coping, including social support and confrontative expression. Individual coping strategies are a unique composite influenced by age, gender, ethnicity, socioeconomic status, past crisis experience, environment, and accessible support.^{82–84} Common behaviors identified under these circumstances include escape/avoidance, spiritual/religious guidance, and several others.⁸³

Philichi⁶¹ modeled family coping dynamics at 2 levels: internally (the way a family deals with difficulties between its members) and externally (the way a family deals with problems in the environment). Ideally, families cope at both levels. Five studies found that coping, particularly problem-focused coping,⁵⁸ is enhanced when parents are active participants in the care of the child.^{58,82,85–87} These and other authors reported a significant correlation between adequate parental coping and clear communication between clinical staff and parents. Minimizing the discrepancy between expectations and reality was found to be a central element.^{11,87–90}

Interventions for Families of Children With Critical Illness

We reviewed 14 studies that evaluated interventions, defined as modification or addition of care intended to ameliorate family impact (Table 7). Many studies reported interventions that were efficacious in stress reduction among critically ill children and their families.^{58,82,86,87,89,91–107} Almost all of the interventions involved clear communication as a prominent feature. Enabling parental caretaking for children with critical illness/injury is preeminent in all successful interven-

†Refs 31, 50, 59, 60, 67, 71, 75, 78, and 79.

TABLE 6 Systematic Literature Review: Family Coping in Pediatric Critical Illness

Author	Design	Study	Outcome Measure	Coping Implications
Braner et al ⁶⁵ (2004)	Prospective, descriptive, case series	Evaluated Web page for PICU children (<i>n</i> = 73), physicians (<i>n</i> = 26), and families and friends (<i>n</i> = 619)	Online survey; computer usage	Web page enhanced parental coping and information access
Dungan et al ⁶⁶ (1995)	Qualitative	Described social work for PICU children and families	Research-based evidence and observation	Coping was enhanced when parents touched, held, and talked to child and were supported by empathetic staff
Harbaugh et al ⁶¹ (2004)	Qualitative	Evaluated nursing care for PICU children (<i>n</i> = 10) and parents	Semistructured interview	Coping was enhanced when parents watched and protected child
Katz ⁷³ (2002)	Prospective, comparative	Compared parents (<i>n</i> = 160) of children with LT and NLT illnesses	4 questionnaires	Mostly used problem-focused CBs; families of children with NLT illnesses used more emotion-focused CBs than those of children with LT illnesses
LaMontagne et al ⁵⁸ (1994)	Quantitative, comparative	Observed PICU mothers (<i>n</i> = 19) and fathers (<i>n</i> = 3)	REA; STAI; 4 questionnaires	Lower catecholamine and stress related to problem-focused CBs
Melnyk ⁶² (2000)	Review	Studied stress, coping, and outcomes of PICU children and families	Research-based evidence	Problem-focused CBs correlated to better outcomes than emotion-based CBs
Melnyk et al ⁶⁷ (1997)	Two-group pilot	Evaluated COPE intervention for PICU mothers (<i>n</i> = 30)	10 measures of stress, anxiety, and participation	CBs were categorized as emotion or problem focused
Miles and Carter ⁶⁵ (1985)	Quantitative	Described CBs of PICU parents (<i>n</i> = 36)	Retrospective self-report; Parental Coping Scale	Problem-focused CBs were most common; close proximity to child was most helpful
Noyes ⁶⁰ (1999)	Qualitative	Observed impact and coping of PICU mothers (<i>n</i> = 10)	Interview	Coping was enhanced when mothers cared for child and nurses provided support
Philich ⁶¹ (1989)	Prospective, descriptive	Described response of PICU families (<i>n</i> = 30)	FACES-III; F-COPEs	Social support improved CBs
Rothstein ⁶⁰ (1980)	Qualitative	Addressed how to help PICU parents cope	Not specified	Parental coping is enhanced by understandable, honest information and knowing who is responsible for care
Tak and McCubbin ⁶⁶ (2002)	Quantitative, secondary analysis of longitudinal	Investigated stress, perceived social support, and coping in families (<i>n</i> = 92) of children with CHD	FILE; CHIP; questionnaire	Perceived social support affects CBs
Youngblut et al ¹¹ (2000)	Review	Portrayed effects of pediatric head trauma on children, families, and parents	Not specified	Coping was enhanced by family participation in child care and frequent, truthful, clear information

CB indicates coping behavior; CHD, congenital heart disease; CHIP, Coping Health Inventory for Parents; COPE, Coping Opportunities for Parent Empowerment; FACES-III, Family Adaptability and Cohesion Evaluation Scale III; F-COPEs, Family Crisis Oriented Personal Evaluation Scale; FILE, Family Inventory of Life Events and Changes; LT, life-threatening; NLT, non-life-threatening; REA, radioenzyme assay; STAI, state-trait anxiety inventory.

TABLE 7 Systematic Literature Review: Interventions for Families of Children With Critical Illness

Author	Design	Sample	Intervention	Outcome Measure	Intervention Implications
Aitkin et al ⁹² (2005)	Qualitative, cohort data review	53 parents and staff; critically ill children	Discharge care; educational tools; support groups	Database of impact, CB, and resources; interviews	The program, "Be ALERT," met parent and patient needs for education and support
Amico and Davidhizar ⁹³ (1994)	Qualitative	Parents of critically ill children	Weekly sessions for parents by a nurse and health care team	Observation and verbal feedback	The sessions helped parents socialize and support each other
Aylott ⁹⁴ (2002)	Retrospective	8 parents of children on ECMO	Narrative interview	Primary and informal interviews; follow-up questionnaire	The interview was therapeutic and decreased fear
Bouve et al ⁹⁵ (1999)	Two-group randomized, controlled trial	50 PICU parents	Letter to parent describing transfer from PICU to floor	STAI 24–48 h before transfer and 1–2 h after transfer	Experimental parents exhibited lower state-trait anxiety levels
Braner et al ⁹⁶ (2004)	Prospective descriptive case series	73 PICU children; 26 physicians; 619 families and friends	Web page with messages for family and friends; progress notes, images, and medical videos for physicians	Online surveys; computer usage	Web page was convenient communicative tool
Curly ⁹⁶ (1988)	Quasi experimental	33 PICU parents	NMPMC included open and direct questioning	PSS; PICU issued 24–48 h after admission, every 48 h, and 24 h after PICU discharge	NMPMC correlated to less stress in parent-child relationship
Curly and Wallace ⁹⁷ (1992)	Quasi experimental	56 PICU parents	NMPMC delivered by staff nurse	PSS; PICU issued 24–48 h after admission, every 48 h, and 24 h after PICU discharge	NMPMC correlated to reduced parent stress; more effective for parents of young children or those previously in a PICU
Dungan et al ⁹⁸ (1995)	Qualitative	PICU children and families	Existing social work	Research-based evidence and observation	Effective interventions enabled parenting skills and encouraged cultural sensitivity
Fiser et al ⁹⁹ (1984)	Qualitative	Parents of 22 PICU patients	Existing services for parental stress reduction	Structured interview	Parental stress was reduced by positive parent-staff relationships, meeting basic needs, and parental participation
Harbaugh et al ¹⁰¹ (2004)	Qualitative	19 PICU parents; 10 PICU children	Existing nursing care	Semistructured interview	Helpful nursing behaviors: supported parental roles and allowed family near ill child
LaMontagne et al ¹⁰⁰ (1994)	Quantitative, cohort, comparative	19 PICU mothers; 3 PICU fathers; 17 PICU children	Existing services for parental stress reduction	REA, STAI; 4 questionnaires	Interventions to assist coping included encouragement of parental involvement and updates at regular intervals
Melnik et al ¹⁰¹ (2004)	Randomized, control trial	163 PICU mothers	COPE intervention delivered after admission, unit transfer, and discharge	BASC, PSI-C; 9 stress, anxiety, and participation measures; questionnaires	COPE mothers interacted more with child and exhibited less stress; COPE children exhibited enhanced mental health
Melnik et al ¹⁰⁷ (1997)	Two-group pilot	30 PICU mothers	COPE intervention delivered after admission and unit transfer	POMS; PSS; PICU; 8 measures of stress, anxiety, and participation	COPE mothers gave child more emotional support and exhibited less stress and PTSD
Wade et al ¹⁰⁵ (2004)	Qualitative	6 children with TBI; 5 siblings; 8 parents	Weekly video conference by psychologist	Surveys: relationship measure; interview	All child-parent relationships improved

ALERT indicates Act, Listen, Educate, and Respond to Trauma; BASC, Behavioral Assessment System for Children; CB, coping behavior; COPE, Creating Opportunities for Parent Empowerment; ECMO, extracorporeal membrane oxygenation; NMPMC, Nursing Mutual Participation Model of Care; POMS, Profile of Mood States; PSI-C, Posthospital Stress Index for Children; REA, radioenzyme assay; STAI-State-Trait Anxiety Inventory; TBI, traumatic brain injury.

tions that have been described.⁵⁷ Intervention strategies specifically tested, such as the Nursing Mutual Participation Model of Care and the Creating Opportunities for Parent Empowerment intervention, have increased parental participation at their core.^{87,96,97,101} In addition, provision of hospitality interventions such as meal vouchers, sleeping accommodations, transportation and parking, laundry facilities, and telephones⁸¹ are significant for families who are struggling with conflicting emotions and responsibilities.⁵⁷

Woodsfield⁹⁷ relates that the PICU nurse's role of careful observation and recording enables recognition of coping strategies, assessment of their effectiveness, and unmet parental needs. It is interesting to note that PICU nurses were the predominant investigators in interventions to mitigate family impact.‡ In addition, a report from St Jude Children's Research Hospital¹⁰⁹ indicates that awareness of staff member vulnerabilities, peer support among staff for each other, and intellectualization were enhanced when transdisciplinary staff communication was open. This study indicated the possibility of substantial, easily implemented change.

Successful interventions do not always depend on human-to-human interaction.^{87,95,99,101,104,105} Use of electronic and Internet-based technologies may enhance communication between the professional team and family members and can deliver, modify, and monitor therapy.^{87,105} In a small study of 6 families of children with traumatic brain injury, Wade et al¹⁰⁵ reported that all 5 siblings demonstrated evidence of improved relationships with parents after a Web-based intervention. Authors of 3 studies varied timing and type of such interventions and found that a combination of preadmission and ongoing information seemed to be especially effective.^{58,98,103} Although this "scheduled" approach to minimizing family stress may be uniformly applicable to only a small number of PICU families, it merits additional study. We did not find comparative studies of relative efficacy among technologies in sibling intervention programs.

DISCUSSION, LIMITATIONS, AND CONCLUSIONS

Many studies excluded patients with a history of chronic illness, previous hospitalization, or child abuse, thus limiting the applicability of their findings. Most samples were limited to English-speaking families and white, married mothers. This is a significant limitation of existing science that might inform effective change for families with critically ill children. Although we acknowledge the need for additional descriptive studies about families facing the uncertainty of chronic illness and disability in their children, we caution that such studies must be inclusive of the demographic realities of childhood critical illness and injury. Although we believe that

our search was comprehensive, thorough, and productive, we may have overlooked significant contributions to understanding family impact in critical illness and injury. For example, we were unable to interface extensively with the economic, anthropologic, sociologic, and demographic literature that might inform or add contextual meaning to the work reported here. The majority of literature reviewed involved the PICU as a common denominator. Presentation of pediatric critical illness/injury in other settings was not heavily included because of the paucity of related articles.

There is a broad spectrum of variability in the responses of parents and siblings to the PICU environment, but certain generalizations seem justified. The admission of a child to the PICU, emergently or postoperatively, imposes severe and often overlooked stressors on the entire family. Several needs of parents and other family members seem readily apparent. Professional practice at every level and discipline should encompass care for these family needs: rest, nutrition, hydration, communication, and a sense of partnership with the staff. On the basis of our review, we conclude that such resources are readily available and would hope that practitioners of pediatric critical care medicine, nursing, and surgery will incorporate heightened awareness of family stressors and needs into their practice.

Specific stress symptoms of family members (parents and siblings) as they vary with less traditional family structures remain understudied. There is urgent need for study of stress patterns in our heterogeneous PICU families. These heterogeneous families are blended, extended, multigenerational, and headed by gay/lesbian, single, and nontraditional parents. They represent both affluence and poverty, but the incidence of traumatic injury, perinatal residual morbidity, and limited access to resources that might mollify childhood injury/illness are far more prevalent in disadvantaged cultural and ethnic groups. This broadening of the research basis of pediatric critical care practice should be transdisciplinary and, ideally, led by health care professionals with doctoral preparation in ethnography, anthropology, sociology, and psychology.

Many studies duplicated one another in finding similar impact patterns of stress: anxiety, social disruption, physical malaise, weakness, and sickness. Data about marital/relationship dissolution, family disruption, long-term functional, and economic effects, particularly in the setting of a family attempting reintegration of a chronically ill and/or disabled child, are remarkably few. Employment loss in parents and caregivers with subsequent decrement in family economics and sibling opportunities might be expected. Marital dissolution and family break-up after certain events that bring families to the PICU (eg, traumatic injury and near-drowning) are said to be common, but we did not find large studies definitively supporting or refuting these beliefs. Few studies

‡Refs 58, 91, 93, 96, 97, 99, 103, and 106–108.

clearly described father and sibling stressors and responses. Existing studies varied substantially in structure and scope, and observational cohorts were too small to yield generalized findings.

Our review certainly demonstrates the need for refinement of research methodology. As larger cohorts are available for collaborative study, particularly in the new NIH/National Institute of Child Health and Human Development Collaborative Pediatric Critical Care Research Network, it is imperative that multidisciplinary research into the family impacts of childhood critical illness and injury be conducted. More studies discerning interaction among risk factors and how they affect families are needed to minimize subsequent disability and dysfunction.

Uniformly, we found that existing studies suggest that coping behavior is enhanced when family members are actively involved in the child's care and receive straightforward information. Ensuring that all medical and surgical personnel at every level receive training in family counseling and interaction under crisis circumstances is a responsibility that could be assumed by faculty. There is wide variation in curricula in pediatric critical care practice disciplines; this is an area for potential transdisciplinary change.

Culturally appropriate care should be the norm in dictating practice in the PICU. We found that existing studies suggest this, but research lacked focus about altered coping strategies and the potential efficacy of various interventions in nonmaternal family members, various ethnic groups, and nonnuclear families. As more children survive critical illness and injury and the population of disabled children increases, more research to enlighten pediatric critical care practice is urgent.

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APPENDIX 1 Leading Causes of Death and Number of Deaths According to Age: United States, 1980 and 2002

Age and Rank Order	1980		2002	
	Cause of Death	No. of Deaths	Cause of Death	No. of Deaths
1-4 y	All causes	8187	All causes	4858
1	Unintentional injuries	3313	Unintentional injuries	1641
2	Congenital anomalies	1026	Congenital malformations, deformations, and chromosomal abnormalities	530
3	Malignant neoplasms	573	Homicide	423
4	Diseases of heart	338	Malignant neoplasms	402
5	Homicide	319	Diseases of heart	165
6	Pneumonia and influenza	267	Influenza and pneumonia	110
7	Meningitis	223	Septicemia	79
8	Meningococcal infection	110	Chronic lower respiratory diseases	65
8	—	—	Certain conditions originating in the perinatal period	65
9	Certain conditions originating in the perinatal period	84	—	—
10	Septicemia	71	In situ neoplasms, benign neoplasms, and neoplasms of uncertain or unknown behavior	60
5-14 y	All causes	10 689	All causes	7150
1	Unintentional injuries	5224	Unintentional injuries	2718
2	Malignant neoplasms	1497	Malignant neoplasms	1072
3	Congenital anomalies	561	Congenital malformations, deformations, and chromosomal abnormalities	417
4	Homicide	415	Homicide	356
5	Diseases of heart	330	Suicide	264
6	Pneumonia and influenza	194	Diseases of heart	255
7	Suicide	142	Chronic lower respiratory diseases	136
8	Benign neoplasms	104	Septicemia	95
9	Cerebrovascular diseases	95	Cerebrovascular diseases	91
9	—	—	Influenza and pneumonia	91
10	Chronic obstructive pulmonary diseases	85	—	—
15-24 y	All causes	49 027	All causes	33 046
1	Unintentional injuries	26 206	Unintentional injuries	15 412
2	Homicide	6537	Homicide	5219
3	Suicide	5239	Suicide	4010
4	Malignant neoplasms	2683	Malignant neoplasms	1730
5	Diseases of heart	1223	Diseases of heart	1022
6	Congenital anomalies	600	Congenital malformations, deformations, and chromosomal abnormalities	492
7	Cerebrovascular diseases	418	Chronic lower respiratory diseases	192
8	Pneumonia and influenza	348	HIV disease	178
9	Chronic obstructive pulmonary diseases	141	Diabetes mellitus	171
9	—	—	Cerebrovascular diseases	171
10	Anemias	133	—	—

— indicates that the category was not available.

SOURCE: US Department of Health and Human Services, Centers for Disease Control and Prevention, National Center for Health Statistics. *Health, United States, 2004 With Chartbook on Trends in the Health of Americans*. Hyattsville, MD. National Center for Health Statistics; 2004:92. Available at: www.ncbi.nlm.nih.gov/books/bv.fcgi?rid=healthus04.chapter.chartbook.

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