

***Report of the Children & Adolescents Task Force of the  
Ad Hoc Committee on End-of-Life Issues***

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**Task Force Members: David J. Bearison, Ph.D., Ira Todd Cohen, M.D.,  
Anne E. Kazak, Ph.D., ABPP, Elaine C. Meyer, Ph.D., Barbara M. Sourkes, Ph.D., and  
Gary A. Walco, Ph.D.**

**APA Staff Liaison:  
John Anderson, Ph.D.  
American Psychological Association  
Public Interest Directorate**

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## PREFACE

In August of 2000, the APA Council of Representatives voted to establish the Ad Hoc Committee on End-of-Life Issues and charged it with providing oversight and leadership in implementing the recommendations of the Report to the Board of Directors from the APA Working Group on Assisted Suicide and End-of-Life Decisions (Report to the Board; see [www.apa.org/pi/aseolf.html](http://www.apa.org/pi/aseolf.html)). The Report to the Board was limited to discussion of end-of-life decisions and assisted suicide for adults. It did not cover end-of-life issues as they relate to minors because to do so would have required a thorough and thoughtful consideration of child and adolescent cognitive development, family structure and dynamics, and the rights of parents versus the rights of children—tasks beyond its scope and resources. The importance and complexity of end-of-life care for children and adolescents thus led to the following recommendation of the Report to the Board:

*The Working Group recommends that the proposed Ad Hoc Committee on End-of-Life Issues prepare a report similar to this one on end-of-life care and decisions involving minors... (Page 36).*

In order to implement this recommendation, members of the Ad Hoc Committee on End-of-Life Issues concluded that it was critical to assemble a diverse group of experts in the area of children and adolescents and end-of-life care to produce a report on such topics as:

- Major causes and settings of death for children;
- What is known about: (a) effective mental health and psychosocial services provided to children and their families; and, (b) the education of psychologists and other professionals who care for gravely ill or injured children;
- The state of knowledge about clinical, behavioral, cultural, organizational, legal, and other important aspects of palliative and end-of-life care for children and their families;
- What is known about empirically-based methods for communicating treatment options, determining family and child/patient preferences regarding treatment options, resolving conflicts about treatment, assessing and responding to grieving children; and evaluating the quality of care as experienced by children and their families;
- Strategies for improving the scope and application of behavioral and social science knowledge to improve care for children and their families; and,
- Recommendations for increasing the role and visibility of psychologists in multidisciplinary care for children, adolescents, and families faced with the end of life.

At its February 2002 meeting, upon recommendation of the Board of Directors, the Council of Representatives voted to allocate funding to support the formation and two meetings of the

proposed Task Force and charged it with producing a report on practice, research, training, and policy issues for psychologists involved with children and families dealing with the end of life.

At its June 2002 meeting, the Board voted to delay the formation of the Task Force due to budget constraints. At its meeting of February 2003, the Council of Representatives agreed to support the formation of the Task Force through the allocation of 2003 contingency funds.

On July 2003, a selection subcommittee composed of three members of the Board for the Advancement of Psychology in the Public Interest invited the following individuals to serve as members of the Task Force: David J. Bearison, Ph.D., Ira Todd Cohen, M.D., Anne E. Kazak, Ph.D., ABPP, Elaine C. Meyer, Ph.D., Barbara M. Sourkes, Ph.D., and Gary W. Walco, Ph.D. The first and only face-to-face meeting of the task force was held November 21-23, 2003.

## INTRODUCTION

*“When a child dies, it is always out of season. When a child dies, dreams die and we are all diminished by the loss of human potential. Although dying is a part of life, a child’s death, in a very real sense, is unnatural and has a devastating and enduring impact.” (p. xv, IOM, 2003)*

Decline and death in childhood are profoundly sad and upsetting, regardless of circumstance, and there are no norms to guide our responses. The death of a child can be an especially difficult experience for pediatric caregivers because it is so rare that young patients die. For parents, of course, the experience is immeasurably more profound. Their traditional roles, to protect their children and provide for them, are ultimately unfulfilled when a child dies.<sup>1</sup> In addition to bereavement from the loss, there can be a deep sense of grief over the potential for what might have been. Parents may also experience guilt about what has or hasn’t been done during life and question how they might have prevented the death, assume responsibility for the genetic transmission of certain diseases, or second guess various treatment decisions along the way. One must recognize the degree of anguish in these situations—for the patient, for family members, and for care providers—and incorporate it into decision making as there are clearly no purely objective criteria for optimal outcomes in these circumstances (Hilden & Tobin, 2003).

Psychologists have knowledge and skills that they can bring to bear on work with children and families living with life-limiting conditions or who are near the end of life, including clinical evaluation, psychotherapy, and communication skills needed to work with children and families in crisis. They understand physical, cognitive, emotional, social, and spiritual development of children and their implications for working with those near the end of life and understand social systems such as families, communities, and institutions and how they interrelate. Similarly, they have an ecological perspective, incorporating contextual components such as culture into their assessments. In addition, psychologists offer expertise in measurement and assessment that enable them to gather information about coping mechanisms, moderating or mediating variables, and outcomes of psychological adjustment. And, psychologists have research skills that enable them to reframe pressing issues into questions that can be empirically investigated.

### Scope of the Report

The scope of this report encompasses end-of-life care for children and adolescents and the roles that psychologists play both in providing care and in increasing our understanding of these important issues. Because of this, the primary focus is on the deaths of young people that result from chronic conditions and congenital anomalies as these deaths are typically preceded by a period of time where the child may receive palliative care in a hospital, hospice, or home setting. Deaths by homicide, suicide, or other forms of violence are unquestionably significant issues,

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<sup>1</sup> Although the term “parents” is used throughout this report to indicate the primary caregivers and legal guardians of the child, we understand that families have very diverse structures and that the primary decision makers regarding the child’s care may not be, or include only, the biological parents. It is important that psychologists involved in providing end-of-life services understand the structure of the child’s family and relational network. For example, many families are female-headed single-parent families, and in others a parent may be gay or lesbian, with or without a life partner.

especially for children in communities of color who are disproportionately affected by these causes. However, these sudden forms of death are much less likely to involve a period of end-of-life care and so are discussed primarily in terms of the causes of death, and the special burdens families and friends face in coping with these types of death.

In addition, because the focus of the report is on care at the end of life, the grieving and adjustment that takes place after the death of a child is only touched upon briefly. The psychological issues for surviving family and community members can differ depending on the cause of death—whether it is a sudden death of a child from a homicide or trauma or the anticipated death of a child due to a congenital anomaly or a long chronic illness. How families grieve is also strongly determined by culture, both with respect to the rituals related to death and the larger meaning that is attributed to death in the context of spirituality and faith. These are all important issues for consideration, but they are not the focus of this report.

And finally, because the Task Force was charged with focusing on end-of-life care involving minors only, this report does not address issues related to end of life for adults. There are, however, significant gaps in our knowledge about end of life for adults as well, particularly with respect to how these issues affect different populations (e.g., people with disabilities; gay, lesbian, bisexual, or transgendered persons; women; the elderly; people living in poverty; and racial and ethnic minorities).<sup>2</sup>

The report is organized into five sections. The first section provides a general orientation to end-of-life issues for children and adolescents. This orientation includes an overview of patterns of child mortality in the United States as well as a discussion of the unique aspects of caring for children and families near the end of life. The second section discusses clinical roles, ethical issues, and future challenges for psychologists who practice in this area. The third section covers research issues and the fourth section addresses training issues. The final section of the report discusses policy issues for psychologists who seek to advance care and knowledge in this critical area. Recommendations for APA and for psychologists working in this area are elaborated at the end of sections two, three, four, and five.

### **Causes of Death for Children and Adolescents**

In the United States and other developed countries, many infants who once would have died now survive. The proportion of all deaths in the United States occurring in children under age 5 dropped from 30% in 1990 to just 1.4% in 1999 (IOM, 2003). Nonetheless, children still die – approximately 55,000 children ages 0 to 19 died in 1999 (IOM, 2003), accounting for approximately 2% of all deaths in the United States. Although this number may be considered small compared to the number of adult deaths, the implications and reverberations of childhood death are far-reaching for families, friends, schools, and communities. Indeed, the rarity of childhood death contributes, in part, to the sense of profound loss, emotional unpreparedness, and injustice that it evokes.

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<sup>2</sup> See also the report of the *APA Working Group on Assisted Suicide and End-of-Life Decisions*, which focuses on adults ([www.apa.org/pi/aseolf.html](http://www.apa.org/pi/aseolf.html)). As the Working Group noted, “the importance and complexity of end-of-life care for children and adolescents suggest the need for addressing these issues in a separate report...” (p. 4).

Infants account for about half of all childhood deaths, with most infants dying in the neonatal period (i.e., first 28 days of life) due to prematurity and low birth weight (IOM, 2003). Most extremely low birth weight (< 1000 grams at birth) infants who die, do so within a few days of birth, although some may survive for weeks or months (IOM, 2003). For post-natal infants (i.e., older than 1 month and younger than 1 year), Sudden Infant Death Syndrome (SIDS) is the most common cause of death, with deaths typically occurring between 2 to 4 months of age. In contrast to premature babies who never leave the hospital before dying, nearly all SIDS deaths occur in the home.

Children ages 1 to 4 and 5 to 9 years are much less likely to die than infants, accounting for 9.6% and 6.4% of all childhood deaths, respectively (IOM, 2003). The leading causes of death for young children include unintentional injury, congenital anomalies, malignant neoplasms, homicide, and diseases of the heart. The most common unintentional injury for young children is motor vehicle occupant injury, followed by drowning, fire and burns, and airway obstruction injuries (e.g., choking and suffocation). Although survival rates for most childhood cancers have improved dramatically over the past three decades, cancer is the leading disease-related cause of death for children older than one year of age.

For older children and teenagers, unintentional and intentional injuries are the leading causes of death. Injuries account for approximately 30% of child deaths (IOM, 2003). Young adolescents (ages 10-14 years) account for 7.6% of all childhood deaths, whereas adolescents aged 15 to 19 years account for a much greater percentage of the total (25.3%, IOM, 2003). Unintentional injuries (primarily motor vehicular deaths) are the leading cause of death for adolescents; however, the rate for older adolescents is almost four times that of the younger group. Reflected within these child mortality rates are profound health disparities, especially with respect to violent deaths, which are much more likely to occur among African American than for White children (IOM, 2003). Other leading causes of death for these age groups include malignant neoplasms, homicide and suicide, congenital anomalies, and heart disease. The primary causes of cancer mortality among these patients include leukemia, brain and central nervous system tumors, bone and joint tumors, sarcomas, and non-Hodgkin's lymphoma. Both homicide and suicide rates increase as children move through adolescence, with a greater than eight-fold difference between younger and older adolescents for homicide and about a seven-fold increase for suicide.

Congenital conditions are the second overall leading cause of childhood death. Children with genetic disorders and neuromuscular and metabolic conditions may live for many years, or even into the second decade, but with increasing disability and eventual death; this can also be the case for children with AIDS. These children, as well as their families, schools, and communities, require integrated services across the continuum of care in order to maximize physical, cognitive, emotional, social, and recreational functioning during their life, and to preserve and enhance family functioning.

### **End-of-Life Issues for Children and Adults: Similarities and Differences**

Many issues in palliative and end-of-life care for children are similar to those experienced by adults. For example, patients at all ages might suffer from inadequate assessment and

management of pain and psychological distress. And, both children and adults routinely receive advice to initiate treatments without adequate consideration or explanation of their potential to cause additional suffering while offering minimal or no potential benefit. Furthermore, both children and adults routinely encounter fragmented health and social service systems that are confusing, unreliable, insufficient, and exhausting to negotiate.

Although there are many similarities in palliative end-of-life (EOL) care for children and adults, children are not simply small adults and their care presents a number of unique issues. Hence pediatric palliative care can never rely on adult standards applied without consideration of specific developmental issues. It is especially important that parents and those delivering services to ill or injured children consider developmental differences that affect diagnosis, prognosis, treatment strategies, communication, and decision making processes.<sup>3</sup> For example, minors do not have the right to direct their own care, and in most situations parents have legal authority to make decisions about medical treatments for their child. Many children who die are born with rarely seen medical conditions that create substantial uncertainty in both prognosis and medical management. And, because many communities have not had enough experience with these conditions to develop expertise, seriously ill children and their families must often travel far from home for their treatment, removing them from their usual sources of support and placing significant strain on family relationships and finances.

Many of the challenges associated with palliative and end-of-life care for children arise from broader social, economic, and cultural concerns. For example, approximately 15 percent % of children lack public or private health insurance. The coverage that does exist is offered by a myriad of private and state programs with widely differing policies and practices for covering palliative, end-of-life, and bereavement services. Single-parent families, which are increasing in number and many of which are headed by women, are more likely to have lower socioeconomic status (SES) (U.S. Census Bureau, 2003), less access to health insurance (U.S. Census Bureau, 2001), fewer healthcare options, and are less likely to be able to advocate strongly for themselves and their children. Families with same-sex parents are also less likely to have access to employer-based health insurance that covers all members of the household, including children.<sup>4</sup> Children and adolescents living in poor or dangerous communities are at higher risk for a shortened life span, especially when it comes to the risk of dying from violence. It is also important to note that the increasing ethnocultural diversity of the U.S. population has implications for both access to care and the delivery of care for dying children and their families. For example:

*... “children and young families are disproportionately represented among immigrants and thus are especially vulnerable to misunderstandings related to differences in language, cultural experiences, and values about life, death, and medical or nonmedical therapies” (p. 7, IOM, 2003).*

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<sup>3</sup> An expanded discussion of issues related to adolescent decision making at end of life can be found in Appendix A.

<sup>4</sup> Although same-sex partner benefits are increasingly available through employers, most gay or lesbian parents do not have the option of receiving health care coverage through their partner’s insurance plan.

## Overarching Themes

During the course of developing this report, members of the Task Force identified a number of overarching themes that are critical to understanding the general context of practice, research, training, and policy associated with children and adolescents near the end of life and their families. Those themes include:

- The normal developmental processes of children and adolescents (e.g., cognitive, physical, emotional, spiritual) must be taken into consideration when addressing the treatment and care of children near the end of life;
- There are many important roles that psychologists can play with respect to end-of-life issues for children and adolescents; however, there are few psychologists working in this arena and their roles are sometimes not well-defined or broadly understood in medical settings;<sup>5</sup>
- Addressing the treatment and care needs of children near the end of life and their families requires specialized skills and training;
- There are no systematic efforts to train psychologists in end-of-life issues for children;
- Despite the many contributions that psychological research may potentially have to improve palliative and end-of-life care for children and adolescents and their families, little research has been developed in this area;
- End-of-life issues for children are psychological and spiritual as well as physical;
- End-of-life care and the death of a child is qualitatively different from the death of an adult—both for families and for caregivers;
- It is essential that psychologists working with children near the end of life be integrated with and work collaboratively with other members of the multi-disciplinary care team;
- Family-centered approaches are critical and therefore it is critical to integrate families throughout the end-of-life process;
- The increasing ethnocultural diversity of the U.S. population has important implications for tailoring end-of-life services to meet the needs of children and families from all backgrounds; and,
- Although insufficient attention has been paid to end-of-life issues for children and their families, interest in these issues is growing.

## PRACTICE

Psychologists in pediatric medical settings typically work as part of multi-disciplinary care teams of physicians (at various levels of training and specialization), nurses, physical therapists, occupational therapists, speech-language pathologists, social workers, pastors, and child life specialists. Team members often share competencies and responsibilities, but each member also has distinct contributions to make in the care of pediatric patients and families.

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<sup>5</sup> We note that rehabilitation psychologists primarily work in large, coordinated, health care and community teams with well-defined and well-understood roles. This combined professional-community-consumer team approach has been a key component of rehabilitation psychology theory and practice for over 50 years, and there is significant research in this area which may be helpful to those working with children near the end of life.

Sometimes there can be challenges in integrating the psychologist into the multi-disciplinary care team. For example, families may refuse to see a psychologist because of concerns about appearing “crazy, weak, or troubled.” Other encumbrances include lack of availability, reimbursement concerns, and care team members not wanting to “introduce yet another new face.” One of the challenges for psychologists working in these teams is to clarify their role and to communicate clearly what key skills they have to contribute to palliative care, end-of-life care, and bereavement—doing this is essential so other members of the team will know how best to integrate a psychologist into the team.<sup>6</sup>

Psychologists clearly have a role within the multidisciplinary care team in providing grief counseling and emotional support for families, and in supplying an outlet for the expression of guilt, anger and confusion, as well as in assisting families with the decision making process (e.g., concerning do-not-resuscitate orders, hospice planning, and funeral plans). As one physician said:

*“Often I need help with the overwhelming sense of loss. I am not a good counselor in this situation.”*

Psychologists are viewed as a resource for differentiating between normal and pathological responses to illness and dying, as well as a “neutral” party with whom the patient can discuss grief, anger, and fears. And, they can serve as a conduit between the child and his or her family to communicate the patient’s concern for the parents and the decisions they are making. Psychologists are also viewed as a resource for helping parents, siblings, and other people in the child’s life to talk about and deal with the death of the child.

*“[Someone to] provide developmentally appropriate emotional support [with a] willingness to explore feelings and thoughts and clarify the end-of-life process.”*

Convening and leading support and debriefing sessions for staff to deal with loss, hostility, guilt, and failure is another role identified for psychologists. This is especially true around the time of delivering “bad news,” transfer to and from the critical care unit, and death.

*“We need an objective third party with a better understanding of the grief process and family dynamics, someone able to help others articulate their feelings.”*

Understanding the grief reaction, family dynamics, depression, and cognitive and emotional development are special areas of knowledge that psychologists can bring to the end-of-life context. Special skills include communicating emotionally charged material, helping others articulate feelings, understanding complex interpersonal interactions, considering responses at emotional and cognitive levels, and being an objective third party for the health care team.

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<sup>6</sup> Information and quotes in this section are derived from a set of informal key informant interviews conducted by Task Force member Ira Cohen who gathered anecdotal information about how the role of psychologists is perceived in medical care settings. Respondents represented departments of adolescent medicine, anesthesiology/pain, cardiology, critical care, emergency medicine, general pediatrics, hematology, oncology, pulmonology, and surgery.

*“Psychologists bring forth their expertise in talking about the process of dying from an emotional and intellectual perspective (developmentally appropriate) whereas we [physicians] usually start at the physical and physiological aspects.”*

## **Roles for Psychologists in Pediatric Palliative Care Settings**

Psychologists engage in many activities and play many different roles in pediatric palliative care settings. General descriptions of psychological components to pediatric palliative care can be found in a number of resources (Bearison, in press a; Frager, 1996; ChIPPS, 2000; Stevens, 1998; Walco & Cohen, in press). Because defining specific elements in detail would produce a compendium of interventions in pediatric health psychology that is well beyond the scope of this document, we focus, in this section, on several critical activities that psychologists engage in most of often.

### **Improving Communication and Strengthening Relationships**

Good communication and positive family-clinician relationships are essential in pediatric palliative and end-of-life care (Contro, Larson, Scofield, Sourkes, & Cohen, 2002; Meyer, Burns, Griffith, & Truog, 2002; Wolfe, Grier, Klar, Levin, Ellenbogen, Salem-Schatz, Emanuel, & Weeks, 2000). Psychologists clearly have a role in modeling, orchestrating, and teaching honest and respectful communication with families, and in creating hospital unit and institutional infrastructure to assure quality family-staff communication, including the integration of ethnocultural aspects of illness and death.

Childhood death often follows an explicit negotiation between the family and health care team about such details as the time, location, and trajectory of dying. Most children die following aggressive treatment and, for nearly three-fourths of children, the most proximate cause of death is withdrawal of life sustaining therapies (Burns et.al., 2000). Discussions about these extraordinarily difficult decisions place a premium on open and effective communication. Additionally, the principles of family-centered care that underlie optimal pediatric palliative care require ongoing communication and partnership among patients, their families, and health care providers.

In its recent report entitled, *When Children Die*, the Institute of Medicine (IOM, 2003) emphasized that end-of-life conversations, care, and policies need to be sensitive to families' cultural backgrounds and values. Indeed, all contexts of end-of-life care are shaped by culture, including the meaning ascribed to illness, the actual language used to discuss sickness and death (including whether death may be openly acknowledged), the symbolic value placed on a child's life and death, the lived experience of pain and suffering, the appropriate expression of pain, the styles and background assumptions about family decision making, the correct role for health care providers to assume, the care of the body during and after death, and appropriate expressions of grief (Koenig & Davies, 2003, p. 510). Due to birth rates in some communities and greater immigration rates among the young, the diversity in the U.S population is greater in the youngest

age groups, making issues of cultural diversity even more pressing in pediatric palliative care population.

In an increasingly diverse society, the goal of excellent communication about palliative care options and processes, which can be difficult under the best of circumstances, can unfortunately become a significant obstacle to care. Even when families and care providers share a common language and culture, negotiating about the appropriateness of clinical services and honoring the wishes of families is a complex and challenging task. Those communication challenges are compounded when the child's family and the health care providers do not share or understand the same language or fundamental assumptions and goals for end-of-life care. Differences in social class and religious backgrounds can further accentuate the profound communication challenges that pediatric palliative care presents.<sup>7</sup>

In a retrospective study of the quality of pediatric palliative care, families identified confusing, inadequate, and uncaring communications regarding treatment and prognosis as problematic and not uncommon (Contro et al., 2002). Even when communication was described as generally positive, families offered suggestions for improvement, including the preference for someone familiar to deliver difficult news, preparation that bad news would be forthcoming, honesty, use of direct and non-technical language, and allowing for hope. Negative communication incidents with staff members, however infrequent—such as insensitive delivery of bad news or perceived disregard for parents' judgment—were long remembered by families and contributed to unresolved feelings and complicated the grieving process. The needs of Spanish-speaking families were not well met; the language barrier between these families and staff affected many aspects of the care. The lack of a common language compromised the parents' ability to acquire and to fully understand their child's medical condition, treatment, and prognosis (Contro et al., 2002). Other groups who do not speak English are likely to experience similar issues. Although many hospitals employ professional translators, it is not unusual to have long waiting periods, multiple interpreters for each case, and times when translators are simply not available. Furthermore, although translators are a critical tool for bridging language barriers, their use does not assure cultural understanding or sensitivity.

The work of Wolfe and colleagues (2000a & b) on the symptoms, suffering, and palliative care experiences of childhood cancer victims offers insight into the complexity and need for improved end-of-life communication, and potential roles for psychosocial clinicians. According to parental reports, nearly 90% of childhood cancer victims suffered at the end of life, most commonly from pain, fatigue, or dyspnea (i.e., difficulty breathing). Furthermore, efforts to control symptoms were often unsuccessful and pain, in particular, was more likely to be reported when the physician was not actively involved in providing end-of-life care. As the children's cancer progressed, parental understanding that their child no longer had a realistic chance for survival was delayed, lagging behind the chart documentation by more than 3 months. Of particular interest, when a psychosocial clinician (social worker or psychologist) was reported to have been involved during their child's illness, there was greater concordance in the timing of physicians' and parents' understanding of the terminal state of the child. That is, families who had the benefit of psychology or social work intervention came to understand sooner that their

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<sup>7</sup> For an excellent discussion of the cultural dimensions of care at life's end for children and their families, see Appendix D of *When Children Die*.

child was dying. More importantly, this earlier parental understanding was associated with earlier integration of palliative care and optimized end-of-life care, including earlier hospice referrals, greater satisfaction with home care, and a greater focus on relief of suffering. Although causality may not be determined from the data, the findings document significant barriers to effective communication at end of life and provide preliminary support that the quality of caregiver communication may play an important role in the integration of palliative care.

In a study describing parental experience of highly technical therapy in the PICU setting, Curley and Meyer (2003) identified the importance of regular family-staff conversations to educate and inform parents and reduce their fears. Parents described a pattern in which more frequent information exchange and conversations about the therapy occurred early in the hospitalization. Typically, greater family-staff communication occurred not only at the beginning of treatment, but also *about* the beginning of treatment. Consequently, nearly a third of parents reported inaccurate expectations about their child's recovery trajectory and, in cases where the child died, inaccurate expectations for the discontinuation of therapy and the dying process. In situations such as these, psychologists can identify and address family-staff communication breakdowns by helping parents to articulate their questions and concerns, serving as advocates, offering a calm non-anxious presence, providing anticipatory guidance, clarifying misunderstandings, and educating staff members about the principles of good communication and therapeutic relationships.

Family experience and satisfaction with hospitalization often rests with the quality of family-staff communication and the extent to which parents and staff members are engaged in partnership (Homer, Marino, Cleary, Alpert, Smith, Crowley Ganser, Brustowicz, & Goldmann, 1999). Families rate the communication skills of clinicians as having equal or greater importance than their clinical skills (Hickey, 1976; Molter, 1979). Unfortunately, strained and limited family-staff communication is often cited by family members as problematic and in need of improvement. Azoulay and colleagues (2000) reported that half the families of intensive care patients experienced inadequate communication with physicians. Similarly, in a study examining what is wrong with end-of-life care, Hanson and colleagues (1997) reported that 44% of families suggested improvements emphasizing communication skills and access to health care providers. When Spanish-speaking families were unable to communicate and have understood their cultural expectations that physicians show their child affectionate attention, their trust and confidence in the care suffered (Contro et al., 2002). In a recent review of the psychosocial issues associated with children and adolescents with terminal illness, Stillion and Papadatou (2002) concluded that good palliative care demands optimal communication among professionals, family members, and schools. These authors go even further, stating that communication among professionals, children, and parents needs to be *radically* improved to insure quality of life in the face of impending death.

Quite commonly, communication problems between families and the team may be attributed to mismatches in expectations, styles, cultural misunderstandings, and needs relative to how much, how soon, and by whom information should be exchanged. For example, problems can arise when family members want immediate and complete information about their child, and the clinician they wish to hear from (often the most senior clinician) is either unavailable or unable to meet to discuss the situation. Families may feel underinformed, underinvolved, or even left

out of the process, and subsequently experience a host of emotional responses to the situation. Some clinicians may adopt a style in which they share information and consult families on a “need to know basis” that might seem quite reasonable to them, but might be experienced by the family as unsatisfactory, patronizing and/or incendiary. In some cultures, the typical focus on parental decision making may be too constricted where involvement of elders or leaders in the extended family, clan group, or community may be appropriate and helpful to the decision making process.

Communication problems can also arise when family members are reluctant to meet with the team. Sometimes families or particular family members choose not to take a participatory decision making role but instead choose to defer to the team. In some cases, communication problems can arise between the family and the care providers when there are culturally different expectations and experiences, especially when those differences have to do with how they view their respective roles in the decision making process. Communication challenges can also arise when multiple clinicians speak with the family and clinician differences in word choice, body language and the expression of hopefulness leave family members confused. In situations when clinicians have differing opinions and recommendations, family members almost invariably tend to align with the clinician who presents the most hopeful outcome. Family-staff communication and relationships can be further strained in these situations when team members are unable to come to consensus.

The burden of critical illness and threatened death of a child is enormously stressful for families and communities. It can undermine the parental sense of competence, control, and stability even under the best of circumstances (Meyer, Snelling & Myren-Manbeck, 1998 Meyer et al, 1996). Communication challenges often arise when there are differences of opinion and strong feelings about continuing aggressive curative care or redirecting to palliative care and withdrawal of life support. Conflict and communication difficulties can also develop and flare among family members when there are complex issues of culpability, shame, guilt, and blame associated with the child’s illness and threatened death. For example, family members may struggle deeply and communication can deteriorate when a child is an unrestrained victim of a motor vehicle accident and when a near-drowning occurs under the supervision of one parent. Families whose children and adolescents present with socially stigmatized situations such as suicide attempts, drug overdoses, or gunshot wounds face unique difficulties that can add to the sense of vulnerability and difficult communication. Families in which there is underlying acrimony or conflict between the parents, separation, and/or divorce often present especially difficult communication challenges. This can include situations where a relationship between a biological parent and his or her partner is either unrecognized or disapproved of by the other biological parent or key family members.

Given the tremendous need for good end-of-life communication and care, this is an opportune time for psychologists to develop viable roles in teaching and modeling how to best communicate in end-of-life settings. Psychologists can help to assess and integrate the ethnocultural characteristics of the child and family into end-of-life conversations and decision making. Beyond teaching and modeling good communication skills, psychologists are also in a position to address the larger issues of clinician anxiety management and the development of relational skills.

### **Facilitating Decision Making**

Several decision making factors are important to parents who must face and make end-of-life decisions on behalf of their children. A sample of 56 parents whose children had died in the pediatric intensive care unit (PICU) reported that their most important decision making factors had been child's quality of life, chances of getting better, and the perceived pain or discomfort of the child (Meyer, Burns, Griffith & Truog, 2002). Eighty-two percent of parents reported that the child's quality of life was very important to them, 78% reported that the child's chance of getting better was very important to them, and 76% said that the child's pain or discomfort was very important. Other factors influencing parental decision making, in descending order of importance, included: the child's unlikelihood of surviving; what the parent believed the child would have wanted; information that the hospital staff provided; religious/spiritual beliefs; and the way the child looked or behaved. Factors that were least often reported as very important to end-of-life decision making included the advice the hospital staff provided; attitudes of hospital staff; and advice provided by family and friends. No parent rated the financial cost of the hospitalization as very important to the decision making process. Thus, many factors can potentially play a role in parental end-of-life decision making. How these factors, and others, can influence decision making for any given parent is complex and likely affected by the child's illness condition and death trajectory, previous illness and loss experiences, and the family's religious and sociocultural background.

Psychologists may be in the position to help parents articulate what matters most to them in approaching end-of-life decision making. Psychologists may also fulfill roles in convening and facilitating difficult conversations at end of life within families, and between family members and care providers. Similarly, psychologists may participate in teaching and modeling the principles of good family-staff communication and relational abilities when difficult news must be discussed and decisions made. In conversations at end of life, psychologists would do well to remember that the child's quality of life, likelihood of getting better, and perceived pain or discomfort need to be regular topics of discussion between family and care providers. Adult patients and parents alike have emphasized wanting to know the "big picture" and "the bottom line" of the illness, expected course, and likelihood of survival, rather than merely the details of the treatment (Singer et al., 1999; Meyer, DeMaso & Koocher, 1996).

### **Facilitating Bereavement**

There is always a need for good psychoeducation for families and staff members regarding the conceptualization and understanding children have of death, sibling support, coping during acute grief, and the bereavement process. Following the death of a child, family members may also seek psychological support and bereavement work. Bereaved parents report feelings of depression, anxiety, anger, guilt, and social isolation (Applebaum & Burns, 1991; Martinson & Papadatou, 1994). Surviving siblings are also at increased risk for behavioral and emotional difficulties (Applebaum & Burns, 1991; Birenbaum, Robinson, Phillips, Stewart, & McCown, 1989; Hogan & Greenfield, 1991). The aftermath and adjustment following childhood deaths due to trauma, accident, inflicted injury, and suicide can be especially difficult and complex for parents and family members, and the services of psychologists can be much needed and sought.

### **Faith and Spirituality in Pediatric Palliative Care**

The literature suggests that faith and spirituality are core aspects of patients' and families' coping efforts when faced with life-threatening illness and death (Barnes, Plotnikoff, Fox, Pendleton, 2000; Davies & Brenner, Orloff, Sumner, Worden, 2002; Davies & Connaughty, 2002; Kane, Barber et al, 2000; Mueller et al., 2001). Several taxonomies of adult quality of end-of-life care incorporate spiritual and existential beliefs and well-being into clinical care models (IOM, 1997; Emanuel & Emanuel, 1998; Singer et al., 1999). However, Davies et al. (2002) report that practical engagement of spirituality in pediatric palliative care has been "virtually neglected." This state of affairs prompted the Children's International Project on Children's Palliative/Hospice Services to develop guidelines to address spiritual issues in dying children and their families (Davies et al, 2002). Similarly, the American Academy of Pediatrics has developed basic guidelines to help pediatricians incorporate spirituality and religious traditions into practice (AAP, 1997).

Children often possess a great spiritual curiosity (Coles, 1990). They can naturally seek God or a higher power and the meaning of life and death. In addition, they may have many thoughts and questions about their faith and religion. Shelley (1982) purports that children have a natural interest in God and an inherent sense of the divine world that may or may not be nurtured by the family and community. The following excerpt from a 7 year-old boy's journal written for school (Meyer et al, under submission) illustrates a surprisingly deep interest and questioning of his spiritual and religious world:

*I wonder if there is a after life? Do you meet god there? I wonder if there is a speshal way to get there? Is heven and a after life the same? Is the difrent religents separated into difrent groups? If you are good do you go? If you are bad do you go? If you are bad do you have a punishment after you die? Do you feel you are still alive after you die? Does your hole body go and leve the bones behind? Do you not feel you are in heven and only your spirit knows? Can your spirit fly to heven? Do you all live in god's house?*

Though limited in number, studies of spirituality in seriously ill and dying children confirm that children do have thoughts, feelings, and questions about prayer and God or a higher power (Himmelstein, Hilden, Boldt, & Weissman, 2004; Pehler, 1997; Wilson, 1994). In one study of hospitalized adolescents, the significance of spiritual and religious issues increased as the severity of illness increased (Silber, 1985). Bearison (1991) found that God and prayer were common themes in the narratives of children talking about what it is like for the to have cancer. Similarly, Stern and colleagues (1992) examined the relationships among health, religion, and spirituality for children found that spiritual and religious practices are prevalent and often perceived by children to be helpful. Specifically, within the cystic fibrosis population, of the 70% who sought non-medical therapy, 60% invoked religious rituals such as prayer, pilgrimages, and the possession of religious objects. Of those who participated in group prayer, 65% reported its frequent use and 92% reported perceived benefits. More broadly, a child's and family's sense of spirituality and/or participation in a religious community may provide a means for positive coping and feeling supported in the midst of difficult circumstances, including illness and

premature death (Barnes et al., 2000). Different religions may further provide interpretations of illness, suffering, and death that the child and family may draw upon in their efforts to cope and to make meaning of the situation.

Parental spiritual and religious experiences and worldviews—including their ethnic and cultural backgrounds—can affect how parents understand and respond to their child’s illness or disability (Barnes, 2000; IOM, 2003). For example, parental spiritual and religious views and traditions have been reported to influence decisions regarding withholding or withdrawing life-sustaining therapies (Kirschbaum, 1996; Meyer et al., 2002). Parents of dying and deceased children have identified not only the relevance and need for spiritual support in hospital and community settings, but also that these needs go largely unmet in the current practice environment (Davies & Connaughty, 1996; DeVeber, 1995).

In newly emerging work in the pediatric intensive care unit (Meyer et al, under submission), many parents acknowledged the centrality and importance of faith and spirituality in their efforts to make meaning of the end-of-life circumstances, to provide guidance and permission around end-of-life decision making and care, to better cope, and to provide emotional comfort. Parents described a number of ways in which their faith sustained them and offered comfort including: praying to enlist God’s help and guidance; counsel from hospital and community-based religious personnel; and social and emotional support from faith communities. Of the parents who reported that their faith was important to them, the great majority emphasized its positive aspects in grappling with end of life issues. However, some parents acknowledged their spiritual distress and, specifically, their anger and frustration at their faith. Consider the contrast of these two responses to the questions about what was most helpful and least helpful during their child’s final days (Meyer et al, under submission):

*“My faith and trust in God, who was in charge of Jessie. Knowing she would not suffer no more when she went to be home to be with the Lord.”*

*“Just when I needed my faith, I hated it, for deceiving both my child and myself!”*

As psychologists, it is important to recognize the potential importance and place that spirituality and religion may hold for dying children and their families as well as the great diversity of beliefs that they may embrace. Coming face-to-face with significant adversity, such as the serious illness or death of a child, can lead some families to turn to their faith for sustenance, meaning-making and an active means to cope. For others, such adversity may lead to questioning, anger, or rejection of their faith beliefs and practices. Others may be atheist or agnostic and reject faith-oriented responses. Creating a culture of acceptance and integration of diverse spiritual worldviews is recommended where clinicians are open to and attend to matters of faith, and where collaboration and referral to religious personnel are part of the work that psychologists do.

### **Negotiating Ethical Issues**

Providing care at the end of life can present numerous ethical challenges, whether the patient is a child or an adult. The care of a child during this period, however, presents some unique

considerations. As minors, children—unlike adults—do not have a legal voice about their medical care, and their capacity and need to participate in decisions about their care varies by age.<sup>8</sup> It is often difficult for families to understand that a beating heart is not synonymous with life. And parents—who in the midst of their grief may be loathe to consider any course of action that allows death or results in their child suffering—can find it very difficult to serve as the child’s agent. Thus, psychologists can play an important role in representing the best interests of the child, and in negotiating conflicts that might occur between the medical team and the family, and among family members.

Negotiating the process of a child’s death can be understandably stressful and difficult. Emotions can run high, and the relationship between the family and the treatment team may seem to become adversarial, with each desiring a different course of action. For example, the treatment team may be ready to withdraw life support before the parents understand that death is inevitable for their child, angering the parents or making them feel that their child is not receiving competent care. Alternatively, though less likely, the treatment team may wish to pursue additional aggressive treatments that the parents do not wish for their child (Bearison, in press b). The tenets of the parents’ religion may preclude interventions that the medical team wishes to pursue, or the parent or a member of the team may feel that the child is suffering too much for treatment to go further. Additionally, cultural differences between the family and the care providers—such as in their views of the meaning of death, family member roles, and rituals surrounding death—may lead to conflicts in what they believe are desirable actions or outcomes (IOM, 2003).

Ethical issues can also arise in the case of families where there is a sexual minority biological parent, and perhaps especially if that parent has a same-sex partner. The legal authority of non-biological parents to make medical decisions for minor children can be problematic in these cases, as many states do not recognize same-sex marriages or second parent adoption. In such cases, the family of origin or the hospital may deny the parent with no legal relationship access to the dying child or input into treatment decisions. In some states, the access of even the biological parent may be compromised if custody of the child has been contested on the grounds of parental sexual orientation. Psychologists can play a role in promoting the best interests of the child in mediating these conflicts.

Many of these concerns are not ethical *per se*, but clinical issues that arise from these kinds of conflicting interests and perspectives among the myriad players in pediatric end-of-life care (e.g., attending physician, nurses, social workers, etc.). For example, parents’ perceptions that their child is not receiving appropriate care may be symptomatic of miscommunication or lack of trust. These conflicts are as likely to occur among members of a treatment team as between the team and family. Psychologists can help to resolve such conflicts by not taking sides and by facilitating ways of negotiating that allow full and unfettered expression of a range of conflicting perspectives. Helping people to feel heard, and appreciating differing opinions and perspectives, can help resolve conflicts before they escalate.

Ethical issues also can emerge when the culture of the child and family differs from the dominant culture, introducing additional complexities into the communication and decision making

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<sup>8</sup> For a discussion of ethical, clinical, and legal considerations in adolescent decision making, see Appendix A.

processes. This can occur, for example, if culturally proscribed roles for husbands and wives suggest that only one particular parent should be consulted about the medical care of the child. In a case like this, staff must balance cultural sensitivity with ethical standards and institutional policies.

Nowhere do ethics enter more strongly than in the decision to withhold or withdraw care from the dying child. More than in the case of adults at the end of life, both families and the medical team may be reluctant to concede when “enough is enough.” Who should make the decision to allow death? When is the right time? What should the process be? What happens when there are conflicting opinions among psychologists and other members of the team, or among the team members and families? What about when the opinions of the child are at variance with those of the family, particularly in the case of adolescents, whose cognitive development makes it possible for them to understand the implications of different treatment options in ways that younger children are unable to? When families and medical staff disagree, it is sometimes the case that families are so single-mindedly focused on hopes of a cure or prolonging life that they find it difficult to face the need to consider appropriate end-of-life care. At other times, the child or family may question the value of pressing on with treatment or refuse treatment when the health care team is committed to aggressive treatment intervention (Bearison, in press b). Psychologists can work with the families and the team to resolve these conflicts in ways that are consistent with the ethics of acting in the best interests of a child and the principle of quality of life.

Although the full range of ethical issues associated with end-of-life pediatric care cannot be thoroughly explored in the context of this report, the following questions capture many of the core ethical dilemmas faced by psychologists in pediatric end-of-life care:

- In what ways do institutional rules and practices support or violate the ethics of care? This might pertain, for example, to decisions not to prolong aggressive curative care because hospital administrators see it as a poor use of institutional resources.
- How do psychologists deal with parents who are suspected of being neglectful in their child’s care? To what extent should they be allowed to participate in medical decisions regarding their child’s welfare? This is particularly an issue in cases of inflicted injury.
- Who should have ready access to institutional ethics committees and under what conditions? How might these resources be better accessed by families and staff members and, when needed, integrated into the decision making and care delivery process?
- How can principles of care for end-of-life decisions involving children and their families be defined so as to inform psychologists when and why to make appropriate referrals outside their existing group of care providers?
- What is the ethical responsibility of the treatment team to families after their child has died?

### **Other Roles**

In addition to the roles described above, psychologists may play a variety of other roles in pediatric palliative care settings. These roles include:

- Assessing quality of life to address key issues, including physical comfort (e.g., relieving pain and other symptoms), activity maintenance, and participation in social roles;
- Engaging children and families (including siblings) to enhance psychological functioning and coping, and maximize performance of usual daily activities and participation in social roles, helping them to negotiate the end-of-life process;
- Identifying maladaptive coping patterns and psychopathology (e.g., assessment of depression);
- Addressing concerns pertaining to therapeutic adherence;
- Serving as an advocate for the child and family, often “giving voice” to the child (e.g., making the child’s preferences known regarding pain management, helping to clarify misconceptions, easing preparations for medical procedures, etc.);
- Providing crisis intervention and consultation around complicated, confusing, and conflict situations;
- Promoting continuity of care across environments (including in the community) and over time;
- Providing psycho-education around anticipatory grieving, dying, death, and the bereavement process; and,
- Providing staff support through groups, individually, or informally, including promoting innovative ways of supporting the staff in emotionally difficult medical situations and bereavement (e.g., team meetings, assisting with dealing with feelings of anxiety, frustration, burnout, etc.).

### **Practice Settings for Psychologists Working in Pediatric Palliative Care**

Although it is clear that psychologists have many skills to contribute in this area, what they do and how they do it changes depending in part on the setting in which they work. For example, the role of the psychologist when a child dies from trauma in an emergency room within hours of a motor vehicle accident or act of violence can be very different than situations in which a child dies at home, in hospice, or in an inpatient setting as a result of a lifelong chronic and degenerative disease. In the section that follows, some of the unique issues that psychologists address in various critical and non-critical care settings are described.

### **Practice Issues for Psychologists in Critical Care Settings**

Most end-of-life care for infants and children occurs in the acute hospital setting, often in the neonatal intensive care unit (NICU) and the pediatric intensive care unit (PICU) (IOM, 2003; Levetown, Pollack, Cuerdon, Ruttimann & Glover, 1994; McCallum, Byrne & Bruera, 2000). Some large urban centers may also have specialty units that serve critically ill children with homogeneous clinical diagnoses, such as pediatric cardiac intensive care units (CICU).

When death is imminent, as when life support is to be withdrawn, efforts turn to transitioning the care and room surroundings to accommodate the dying child and his or her grieving family. The psychologist may intervene by facilitating end-of-life conversations within families and between families and staff members, offering anticipatory guidance and lending a supportive presence during the withdrawal of life support. At other times, death is sudden and less expected—the child may die in the midst of “being worked on” or following unsuccessful resuscitation efforts. In these situations, there is not the same opportunity to orchestrate care or to prepare for the death. It is important that the psychologist be knowledgeable and comfortable with procedures such as withdrawal of life support in order to help explain them to families and prepare the family for the inevitable outcome. It is not unusual to be asked direct questions such as “How long will it take?” “Will my baby suffer?” “What will happen?” and “How will we know when she is gone?” Initiating commemorative rituals with the family to remember the child, such as making hand prints or journal writing, and helping families to begin the process of funeral planning can also be meaningful and helpful interventions that are usually done by child life specialists. Familiarity with both non-professional and children’s bereavement literature enables the psychologist to make good recommendations for reading material that will assist families with the grieving process and adaptive coping. Tending to the psychological needs of siblings, in particular, is generally highly valued by parents during this time. Parents themselves often ask psychologists for assistance in talking to siblings about dying and preparing them for visits prior to death, and in obtaining developmentally appropriate reading materials concerning death and grief for their surviving children (Williams & Koocher, 1999).<sup>9</sup> In addition to direct clinical work, psychologists are often called into service to facilitate staff support groups, to develop bereavement follow-up programs, and to offer continuing education programs.

### **Neonatal Intensive Care**

Infants account for about half of all childhood deaths, with most dying within the neonatal period (i.e., the first 28 days of life) due to short gestation and low birth weight (IOM, 2003). Following birth, most neonates requiring critical care are served in NICUs; however, depending on the requirements of their care, transfer to the pediatric intensive care unit (PICU) setting may be deemed necessary.

Given the circumstances and demographics of infant death, there are some important messages for the psychologist. Issues of “who owns the baby” and displacement of parents from their natural caregiving and protective roles can abound in the NICU, and the psychologist can play useful liaison, conflict resolution, and advocacy roles. Although the death of any child is always out of season, the death of a baby who has barely had a chance at life and who has yet to become known, can be especially difficult and seem profoundly unnatural and unfair. Some parents find themselves having to say good-bye to their baby before they truly have had the chance to say hello. In situations of multiple births, parents may find themselves in the extraordinary position of simultaneously embracing life with one child and letting go of life with another. It is worth remembering that many parents in the NICU have suffered previous pregnancy loss or have required assisted reproductive technology (ART) to bring a baby into the world. What should be

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<sup>9</sup> DeMaso and colleagues (1997) offer useful clinical guidelines and suggestions to assist children early in the grief process.

a triumph—giving life to a baby—can end in profound emptiness and despair if the baby does not survive. Such experiences can deepen and influence the grief and loss associated with infant death, and the psychologist is well-advised to understand the place of each baby in the family's life.

Psychological work in the NICU often focuses on the parents, siblings, and extended family, particularly on issues such as the violation of expectations and dependency that early or complicated birth can represent, fears about the baby's survival and well-being, transitions in family life and roles, and adaptive coping. Work in the NICU with infants is qualitatively different than work with older children who can talk, who have lives outside of the hospital, and who have established relationships with their parents. Here, psychologists benefit from a good foundation in infant behavior and development, and an understanding of the medical and neuro-developmental challenges that infants can face (Vergara & Bigsby, 2004). Often, the role of the psychologist in the NICU is psycho-educational and supportive—helping to nurture the infant-parent relationship, establishing the parental role, and helping to introduce siblings to each other (Lawhon, 2002; Meyer & Bigsby, 2004; Meyer, Lester & Boukydis, 1998; Seideman, Watson, Corff, Odle, Haase, & Bowerman, 1997). Participating in end-of-life conversations and care, anticipatory grief work, collaborative commemorative work with the family and staff, and helping to understand and to orchestrate death in a manner that is meaningful and culturally sensitive to families are all possible ways of intervening for the NICU psychologist. It is not unusual for complex ethical dilemmas to arise in the NICU, and the nature of the setting can place staff in a perpetual state of grieving. Since NICUs are regionalized and generally located in urban areas, many families can be displaced from their usual social support systems and separated for substantial periods of time, which can further compound feelings of isolation, failure, and stress for families, and add to the burden of care for staff who oftentimes serve as the surrogate family.

### **Pediatric Intensive Care**

The PICU is a uniquely stressful environment characterized by high-volume acute care where outcomes are uncertain, invasive medical procedures and equipment dominate, and dramatic and frightening changes can occur in the child's appearance and ability to relate (Meyer, DeMaso & Koocher, 1996; Rushton, 1990; Williams & Koocher, 1999). By necessity, there is a focus on medical intervention in critical care settings, with far less attention generally devoted to psychological and developmental issues (Hurt, 1984).

For psychologists who work in PICU settings, palliative care represents a significant proportion of their work. When Williams & Koocher (1999) tracked a year's worth of psychology consultation requests in a busy PICU, they found that 32% of referrals focused on end-of-life grief work with parents and siblings. The setting, however, poses a number of challenges to this work. For example, there may be only limited opportunities to convene family meetings because of the number of professionals involved, time pressures, limited privacy, and scarce space (Drotar, Benjamin, Chwast, Litt, & Vaner, 1982; Rushton, 1990). Psychologists may or may not have had the opportunity to establish previous relationships with the children and their families in the PICU. When critical illness strikes and death threatens, psychologists can find themselves confronted abruptly with the intimate emotional lives of families and be quickly drawn into the

family’s “inner circle” of support (Meyer, Burns, Griffith & Truog, 2002). Thus, the ability to quickly establish rapport, strong interpersonal skills, and crisis intervention skills are critical attributes for the PICU psychologist. Unlike traditional psychotherapy that unfolds over time, in situations of sudden critical illness, accidents and suicide attempts, it is not unusual for psychologists to work intensively with patients, families, neighbors, and school and faith communities over a 1 to 3 day period—sometimes for many hours at a time.

The pediatric intensive care unit serves critically ill patients ranging in age from infancy through young adulthood who present with a wide range of clinical presentations, from congenital anomalies and fatal cancers, to motor vehicle injuries and gunshot wounds. Clearly, the illness and trajectories of dying that children experience are determined, in large part, by the nature of their specific disease or injury. The preterm infant born on the cusp of viability, the youngster born with multiple congenital anomalies, the child diagnosed with a brain tumor, the young teen involved in a fatal motor vehicle accident, and the teenager who commits suicide will have quite different courses and trajectories of dying. Although there are significant individual differences that naturally occur, understanding the range of trajectories of dying that characterize the leading causes of pediatric death is helpful to the psychologist in clinical practice. Such knowledge and experience can serve as guideposts, enabling the psychologist to customize interventions, to provide useful and specific psychoeducation and anticipatory guidance, and to share family perspectives.

Given the range of how children and adolescents may die in the PICU, and the corresponding needs of family members, psychologists need to be flexible and eclectic in their approaches (Meyer, DeMaso & Koocher, 1996). Williams & Koocher (1998) identified training and experience in pediatric psychology, neuropsychology, and cognitive-behavioral therapy as essential tools for working effectively in the PICU. Psychosocial interventions in the PICU require a framework for conceptualizing diverse problems and family situations, working quickly and as part of a team, acknowledging the centrality and role of the medical/surgical issues, and integrating a variety of intervention techniques.

The Medical Crisis Counseling Model (Pollin 1994, 1995), has been described as particularly useful in the PICU setting. This approach enables clinicians to swiftly orient themselves to the problems at hand, focuses on the medical condition, normalizes the emotional distress experienced as a result of medical stressors, optimizes previously successful coping strategies, and identifies problem-solving strategies and concrete suggestions to address immediate concerns arising from the medical crisis (Meyer et al., 1996; Williams & Koocher, 1998). The model also identifies and addresses core clinical issues that can surface in the midst of a medical crisis, including loss of control, dependency on medical staff, fear of expressing anger, and fears about death.

### **Practice Issues for Psychologists in Community Settings**

Psychologists in the community may play a central role in providing services to children near the end of life and their families. Once a child dies, there are a number of reasons a family may not be followed at the original treatment center. Involving individuals in the community early in the end-of-life process allows more relatively seamless transitions to be made. In addition,

psychologists have important roles to play in preventing or addressing possible negative outcomes for community members after the death of a child. These issues are discussed in more detail in the two sections that follow.

### **Community-Based End-of-Life and Palliative Care**

Children with congenital conditions, including fetal malformations and deformities, genetic disorders, and neuromuscular and metabolic conditions, as well as children with AIDS, may live at home and in their communities for many years with special health care needs and increasing disability, and are significantly more likely to die at home (IOM, 2003). Work with such children and their families more often resembles hospice care than it does hospital care. However, the one profoundly important difference from hospice care is that for some children in community settings the process of growth, functional limitation, decline, and death may extend over a period of 10 to 20 years from birth.

For children who are primarily treated in their communities and who may die at home, psychologists may help in a number of ways, including in psycho-educational and supportive roles. They may facilitate the initial communication of the diagnosis and prognosis to the child and family, with understanding of the developmental stages of both. They may assess and intervene to maximize child and family coping and adaptation. They can provide evaluation and treatment focused on maximizing independent activities and community participation, including physical, cognitive, emotional, social, educational, and recreational functioning. They may evaluate and facilitate the use of adaptive equipment and cognitive compensations as well as home, school, and community modifications.

Children with these types of long-term fatal conditions, as well as their families, schools, and communities, require integrated services across the broad continuum of care in order to maximize activity, participation, and quality of life. They often require skilled nursing services, rehabilitation therapies, medical equipment, and intensive educational supports. However, families often report strains associated with caregiving demands and with the complex task of navigating the system of care to obtain a range of services for their child (Krauss, Wells, Gully, & Anderson, 2001). These challenges place family members at risk for psychological distress, especially when there are other life stressors such as economic hardship, marital conflict, limited social support, or significant family role disruptions (Drotar, 2001; Wiegner & Donders, 2000). Psychologists, working with social workers, can intervene to improve the quality of health service delivery in ways that enhance coordinated care and community integration (Farmer, Clark, & Marien, 2003). Such comprehensive care interventions decrease family needs, reduce parental strain, enhance children's school attendance, promote parental work participation, and reduce utilization of medical services (Farmer, Clark, Marien, Sherman, & Selva, 2003; Palfrey, Sofis, Davidson, Freeman, Liu, & Ganz, 2004; Stein, 2001).

### **Preventive Efforts Focused on Communities**

Because the death of a child is uncommon and yet may occur in any age range or setting, prevention efforts must necessarily be broad in their scope. Preparing children and adolescents

for death in order to reduce subsequent psychological difficulties is a small but growing field of interest among psychologists. Kazak and Noll (2004) present a public health model for understanding death from pediatric illness. They propose tailoring types of services provided before and after child deaths to impact the well being of a broad group of families.

Schools are a prime setting in which to conduct preventative interventions for ill children who may die. School reintegration programs developed for children with cancer have also been useful in helping schools adjust and prepare for the likely death of a classmate (Prevatt, Heffer & Lowe, 2000). Specific approaches for helping children understand the death of a classmate are many, including encouraging students to talk about their deceased classmate, identifying feelings about the child and death, and preparing children for ways of saying goodbye to dying classmates by writing letters, talking, or attending funeral services (Madan-Swain, Austin & Taylor-Cook, 2003). Recognizing the broad array of incidents that can result in the death of child at school (e.g., chronic health conditions, injuries, choking, burns, poisoning), several national healthcare organizations have published guidelines for school emergency response programs (Hazinsky, et al., 2004).

Suicide is a well known risk in adolescence. Ideally, the prevention of suicide hinges on both family, in light of the family variables associated with suicidality (Wagner, 1997), and the broader community, including cultural considerations. In the wake of a suicide, attention to those youth most vulnerable to having psychological disturbances themselves is important. For example, there is evidence that sexual minority youth are more likely than their peers both to think about and to attempt suicide (Russell and Joyner, 2001). Opening up channels of communication at home, in school, and in community settings may help identify vulnerable children and adolescents and promote the provision of psychological services for them. Concern for clusters of suicide or the occurrence of “copycat” suicides has been a matter of some controversy. True clusters of suicides appear to be quite rare, in the range of 1 to 2% of completed suicides, although risk for contagion is a valid mental health concern (Gould, Shaffer & Greenberg, 2003). More recent emphasis has been on the impact of the media on suicide clusters, including experimental work related to the perception of news from the media on youth (Gould et al., 2003).

Appreciation for the potentially broad and unexpected events that are traumatic for schools and that can result in death has been heightened in this country in recent years with the visibility of violent incidents (e.g., shootings) and the overarching emphasis on safety in the context of terrorism. Resources for professionals working with schools are available through the internet. Examples include the National Child Traumatic Stress Network (NCTSN, [www.nctsn.org](http://www.nctsn.org)) where the three R’s of School Crises and Disasters (Readiness, Response, Recovery) are presented along with many additional resources from the NCTSN and other organizations. The National Mental Health and Education Center at the National Association of School Psychologists (NASP, [www.naspcenter.org](http://www.naspcenter.org)) also provides materials related to child death in the school context. Planning and preparation are central, with a multi-disciplinary team prepared to respond in a crisis and educate students, teachers, and families about preparing for a child’s death. The site provides guidance for how to deal with a student’s death, including how to verify information about the death, talking with students in a developmentally appropriate manner, limiting information when necessary (as in the case of suicide) and maintaining school routines

while accommodating the needs for safety and support for peers and teachers. These guidelines also include detailed information about death and grief in different cultural groups.

### Practice Challenges for the Future

The field of palliative care for children is relatively new, and many of the needs of patients and their families—and the optimal clinical models and interventions to address them—have yet to be defined. The death of a child does not fit in with the normal progression of life—and as a result normative models are scarce and virtually none has been tested empirically and we need to consider that there are no normative models of dying (Bearison, in press b). At this juncture, we are left with far more questions than answers. Both the Institute of Medicine (2003) report on improving palliative and end-of-life care for children, and the policy statement on palliative care for children from the American Academy of Pediatrics (2000), highlight many of the needs of children at the end of life and identify some general issues for developing clinical models. However, the actual application of such clinical models and documentation of their validity remains to be done.

The psychological adaptation of dying children and their families is part of a process that includes an array of developmental and other contextual factors (Stevens, 1998). A central issue is the difficulty inherent in articulating the desired outcomes of psychological interventions in the context of pediatric palliative care. What constitutes a “good death,” especially during childhood, and can we even begin to define the parameters of a “good death?” How do children, their families, and care providers differ in what outcomes they most value in this process? What does “healthy bereavement” look like in parents over the course of time? What is the effect of the death on siblings and how might we minimize deleterious outcomes for those children? Data from practitioners focusing on adults clearly highlight that psychological well-being is an important element (Steinhauser, Clipp, McNeilly et al., 2000); and yet, we have not characterized the details of quality of life at the end of life for children.<sup>10</sup> There is no clear standard and, in many ways, we are at the earliest stages of research and defining the field. Several key questions emerge for defining outcomes when intervening in a palliative care setting:

- **What is the focus of palliative care?** — Is the focus simply on the dying children themselves, or should parents, siblings, the broader family, the community, and caregivers be included? The manner in which this question is answered will help define the scope of the intervention.
- **Whose perspectives should be assessed?** — Perceptions of the child’s well-being will differ depending on whether information is sought from the child’s own perspective, or through the eyes of parents or caregivers.
- **How should care be organized to assure that it is responsive to the needs of diverse groups?** — People from different ethnic, cultural, or socioeconomic backgrounds, or with different cognitive and physical abilities, for example, may differ in what they consider to

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<sup>10</sup> See Bradlyn, Varni, and Hinds (2003) for a discussion of the status of endeavors in assessing outcomes in this context, as well as citations of available measures of such outcomes.

be appropriate outcomes. Additionally, those preferences may support or conflict with what caregivers see as the goals of intervention.

- **What kinds of models of clinical care are most promising?** — If we focus on quality of life, a generic model will lead us to focus on different outcomes than one that is more specific to particular clinical conditions.
- **What is the time frame?** — Outcomes may be evaluated proximal to the child’s death or potentially months or years later. Even defined outcomes are very likely to change over time and this must be captured or accounted for.
- **When should palliative interventions begin?** — The Institute of Medicine report (2003) suggests that palliative care for children and families should begin at the time of diagnosis. Rehabilitation psychology has developed evidence-based, practical models for assessing and treating children, families, and communities when children have conditions that lead to death over many years. These models involve professional, community, and consumer team participation to maximize age-appropriate functional activities, social participation, family functioning, and quality of life. These models may be helpful to psychologists who work with children with disabilities who live in their communities and die at home.

Despite the gaps in knowledge, it is necessary to articulate the desired outcomes of palliative care programs and to conduct program evaluation. As psychologists join palliative care teams, evaluation of their specific services will also be essential. Outcome research must address both funding issues (e.g., cost effectiveness) and the outcomes for patients, families, and the healthcare team. For example, the Current Procedural Terminology (CPT) codes for health and behavioral assessment and intervention provide an important opportunity to expand the reimbursement of services within a biopsychosocial model (APA, [www.apa.org/practice/cpt\\_2002.html](http://www.apa.org/practice/cpt_2002.html), Noll & Fischer, 2004).

## **Practice Recommendations Related to End-of-Life Care for Children and Adolescents and Their Families**

### **Recommendations for APA**

- Identify and disseminate evidence-based information about working with all children at the end of life and their families;
- Identify and disseminate evidence-based information about how end-of-life-care needs to be tailored for diverse groups of children and adolescents and their families, including those of different cultural and socioeconomic backgrounds, those of different cognitive and physical abilities, women, and sexual minorities;
- Raise awareness, both to the public and within the profession, regarding psychosocial and palliative care issues for all children near the end of life and their families (e.g., develop conferences, written materials, web-based resources, etc.);
- Publish a series of *APA Monitor* articles focusing on these issues;
- Develop a practical guide for psychologists on “What to do if a child with a life-limiting condition is referred to me”;

- Work with news media to develop articles on pediatric end of life;
- Identify psychologists to participate in multidisciplinary initiatives involved with defining palliative care models for children to ensure that more comprehensive definitions of palliative care for children are developed that address the psychosocial aspects of care at end of life; and,
- Collaborate with other professional organizations, regulatory boards, governmental agencies, multidisciplinary initiatives, and medical centers to develop palliative care models for all children to ensure that psychological and psychosocial aspects of care at end of life are addressed.

### **Recommendations for the Practice of Pediatric Palliative Care**

- Psychologists should work to identify and increase understanding of what clinical outcomes are in the best interests of children at end of life and their families (e.g., physical comfort and symptom management, psychological and social adjustment and well-being, spiritual well-being)—including across and among different ethnocultural groups;
- Psychologists should work to identify and increase understanding of clinical interventions and outcomes that are responsive to and supportive of the needs of diverse groups of children and adolescents at end of life and their families, including racial and ethnic minorities, people of different cognitive and physical abilities, sexual minorities, and women;
- Psychologists, in consultation with other disciplines, should devise and evaluate specific and generic models of clinical care for all children at the end of life (e.g., for minimizing psychological stress, and for coping with the death of a child);
- Psychologists should be active members of multidisciplinary treatment teams that deal with end-of-life and palliative care issues;
- Psychologists, working with children at end of life and their families, should have a basic working knowledge of the medical issues involved, including keeping well-informed of the medical status of the child under care and understanding invasive medical procedures; and,
- Psychologists developing care plans for children at the end of life and their families should involve, together with social workers, community-based resources to help assure a continuum of care. Resources should be made available and affordable to assure that these plans can be appropriately implemented for all children and their families.

## **RESEARCH**

Surprisingly little research has been published about end-of-life care, dying and death, and bereavement related to children, adolescents, and their families; this is especially true with respect to considering cultural dimensions of care (Institute of Medicine, 2003).<sup>11</sup> As a result, there is little quantitative or qualitative evidence to support current practices and to advance treatment strategies for the future (Bearison, in press a & b). In this section, several of the

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<sup>11</sup> Although also limited, the field of research on adults and death and dying is further developed than that for children; lessons for pediatric end-of-life care can be learned from this larger body of research.

challenges for conducting research in this area are described, followed by a brief discussion of important gaps in knowledge.

## **Challenges to Conducting Research**

### **Methodological Challenges**

This is a challenging area in which to conduct research. Flexibility in methodology and respect for the autonomy of children and families are essential. Because death in children is rare, it can be difficult to achieve acceptable levels of statistical power in empirical studies without inter-institutional collaboration; this increases the cost, complexity, and effort associated with such research.

To date, most research about childhood death has been retrospective. The promise of prospective studies ushers in a host of additional methodological challenges. A related issue is the stipulation of inclusion and exclusion criteria. When exactly is a child considered to be “terminal” or facing the end of life? Many hours of discussion among members of the palliative care committee of the Children’s Oncology Group have failed to yield satisfactory inclusion criteria for such studies among children with cancer (Walco, 2000).<sup>12</sup>

Because physicians vary in their views of when a condition may be considered terminal, they may also differ in their sentiments about referring participants for end-of-life studies. Even in studies focusing on children with advanced illnesses, preliminary data indicate that physicians are reluctant to refer their patients to end-of-life studies.<sup>13</sup> They may fear, for example, that referral will be seen as a sign that they have “given up” on the child. This constitutes a significant barrier to the development of knowledge that may lead to improvements in care.

Parents will be reluctant to give consent for research on the end of life unless they are comfortable with the team involved. Thus, recruitment and retention of participants may be out of the specific investigator’s control and differential attrition rates must be studied to account for bias in outcome data.

Working with diverse populations presents additional research challenges. For example, different ethnocultural groups may have different attitudes and understandings about participating in research. In addition, language and cultural differences can make it more challenging to negotiate informed consent in ways that are sensitive to the world views of potential research participants and assures their understanding of the issues involved. Involving members of the population groups under study in the development and implementation of the research plan can help to assure that the research questions and processes, and the interpretation of the results, will be meaningful.

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<sup>12</sup> The Children’s Oncology group is a clinical cooperative supported by the National Cancer Institute that is devoted to research on childhood and adolescent cancer.

<sup>13</sup> Research by Task Force member Gary Walco on “Quality of Life Among Children With Cancer Facing Advanced Disease,” funded by the Healing Heart Foundation and the Healthcare Foundation of New Jersey.

Once participants are enrolled in a study, it is important to consider the frequency of assessment. In addition to having to balance demands on the child and family with the need to gather the data, one needs to consider the frequency of measurement given the rapidity with which the factor under question might change. There may be circumstances where the child is no longer able to provide self-reports. Thus, methodologies should include alternative strategies to obtain desired data should this occur. Finally, the end point of observation may be difficult to stipulate, especially when family members or others may continue to be followed after the child's death.

Another concern about research in this area has to do with the rigor of methodology. In a study that maximizes internal validity, not only are inclusion criteria well stipulated, but the procedures for assessment and intervention are fairly rigidly standardized. The more one deviates from the standard, the more internal validity suffers. Because of the variability among participants entering such studies (including among ethnocultural dimensions), as well as the physical and emotional demands of their conditions, adherence to a rigorous methodology is difficult. Thus, increased tolerance for threats to internal validity is necessary.

Measurement is another area of concern. As mentioned above, a psychometrically sound means of assessing outcomes in a pediatric palliative care setting does not yet exist. At this point in the development of science in this area, qualitative research strategies can be especially useful for gathering initial information about key variables (see Bearison [in press b]). Quantitative studies can be utilized to demonstrate reliability, validity, and clinical sensitivity of key variables.

### **Challenges for Defining Outcomes**

One impediment to conducting research in end-of-life care is the lack of clarity regarding outcomes (Himmelstein, et al., 2004). At the level of the child and family, for example, what are reasonable outcomes in this process? What do children, families, and care providers consider to be positive outcomes (a “good death”), and how do those priorities differ across different ethnic, cultural, socioeconomic, or other groups? For example, some families and children may emphasize enhancing activity and participation, while others may focus on pain management and relieving symptoms. And, efforts to involve older children or adolescents in decisionmaking may create conflict for families whose cultural norms are inconsistent with American ideals of self-determination (Koenig & Davies, 2003). Some work addressing these issues has been done with the adult population. A fruitful avenue for research would be to replicate this work for children and adolescents and their families. Existing measures are likely to be of limited value outside of providing discrete assessment of symptoms at particular points. Without a more detailed understanding of the naturalistic course of adjustment, attempts to identify markers of a “good death” or adaptive functioning under adverse circumstances are likely to be of limited value.

### **Ethical Challenges in Research**

The conduct of research on palliative or end-of-life care for children presents a number of ethical challenges. Foremost, attention must be paid to minimize intrusion into the lives of children and families as they confront this catastrophic event and its aftermath. One could argue that, given the emotional tone of the circumstances when confronting the death of a child, any intrusion may

have a degree of risk attached to it.<sup>14</sup> Clearly, burden to the family and child must be minimized. In addition, one must be very clear as to what potential benefit participation in the research has for the child and family, and have an understanding and appreciation of how benefits and burdens might be perceived by people from diverse racial, ethnic, cultural, and socioeconomic groups, as well as those with different cognitive and physical abilities. Potential risks and benefits must then be presented to the parents for informed consent and (if age appropriate) to the child for informed assent (see Appendix A for a discussion of ethical issues related to adolescent decision making). It should be noted that preliminary research retrospectively exploring the perspectives and experiences of parents whose children have died indicates that parents often welcome the opportunity to reflect on their loss with respectful, attentive listeners who want to hear their stories (Contro et. al., 2002).

A major concern arises, however, with regard to consent and assent. Wolfe and colleagues (Wolfe, Klar, Grier, Duncan, Salem-Schatz, Emanuel, & Weeks, 2000) found that care providers recognize the impending death of a child well before it is communicated to the family and well before the family has that awareness. How then might one solicit consent for a study focusing on end-of-life issues if the family is not yet aware of the circumstance? Calling the study something else is potentially misleading and, therefore, is not an appropriate strategy. If one approaches a child for assent, it is essential to first be aware of the child's knowledge of the situation and adjust the assent process accordingly.

In addition, there are regional, local, and idiosyncratic differences among Institutional Review Boards (IRBs). This is especially so with respect to research involving children, in part because the federal guidelines on key issues often are ambiguous, and therefore open to wide interpretation (Shah, Whittle, Wilfond, Gensler, & Wendler, 2004). IRB members tend to be conservative when it comes to protecting the welfare of child participants and objections may be anticipated in research dealing with death in childhood. In particular, IRBs may have misperceptions regarding the willingness of potential participants to be involved in research, assuming that approaching them would be overly intrusive or cause undue emotional distress.

### **Gaps in Research Knowledge**

Although the difficulty of conducting research in this area is undeniable, the unfortunate consequence is an underdeveloped understanding of the processes associated with either healthy or maladaptive outcomes. Clearly, there are many opportunities for work in this area. The sections that follow list priority areas for future investigation.

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<sup>14</sup>Risk-benefit analysis of the potential costs versus benefits of enrolling subjects in research can be divided into four major categories: (a) research not involving greater than minimal risk, (b) research involving more than minimal risk with the prospect of direct benefit to the child, (c) research involving more than minimal risk with no direct benefit but likely to yield important generalizable knowledge, and (d) research not otherwise approvable that presents an opportunity to understand, prevent, or alleviate a serious problem affecting the welfare of children (American Academy of Pediatrics Committee on Drugs, 1995). Some have advocated that young children should only participate in studies that either pose less than minimal risk or studies that provide direct benefit to the participant (Burns, 2003). However, the American Academy of Pediatrics (1995) urges a broader interpretation of benefit to include that which will advance the welfare of children in general.

**Naturalistic course of adjustment before, during and after a child’s death** – Although the death of a child cannot be removed from its context and from the life of the family before, during, and after the child’s death, little research attention has been paid to this prospective process. Additionally, little is known about how psychological outcomes might relate to types of death. In general, psychological knowledge related to the more gradual death of children from chronic illness is more substantial than that related to other types of death. The sudden loss of a child is often assumed to be more distressing than an anticipated loss, but empirical support is lacking for this distinction. Information on the naturalistic course of a child’s death is essential for understanding end-of-life care and bereavement more fully and for identifying intervention targets and time points. Longitudinal studies are particularly needed given the lack of knowledge regarding specific types of death and the contribution of family structure and background (including such important factors as socioeconomic status, ethnicity and culture, sexual orientation, religion).

**Understanding of Diverse Groups** – A firm research base on cultural dimensions of end-of-life care for children and their families is lacking. An extensive review of the research literature reported by Koenig & Davies (2003) found only 20 articles published in the previous 10 years that reported empirical findings related to cultural issues in families with a child who was seriously ill, dying, or who had died—and not all of those focused exclusively on the United States. Additional research is needed about end-of-life care with children and adolescents and their families from ethnically, culturally, and socioeconomically diverse groups, of different cognitive and physical abilities, and of different sexual orientations and genders. This includes, for example, research to increase understanding of which types of interventions might be most effective for different populations, how diversity factors affect access to care, and on the impact of culture and language, literacy, and cognitive ability on decisionmaking, communication, and understanding of consent processes.

Furthermore, very little empirical information is available about the implications of sexual orientation (of both adolescents and their parents) and end-of-life care. Research is needed to better understand, for example, what special concerns there might be when a parent is gay, lesbian, bisexual, or transgendered (e.g., regarding the legal standing and involvement in decisionmaking of the parent or the parent’s partner), or when the child is (e.g., with respect to available support from peers).

**Child death in the context of family, healthcare setting, and community** -- A family systems orientation to research in end-of-life care can build on existing research in family adjustment and be inclusive of multiple members of the family system (e.g., parents, siblings, parental life partners, stepparents, grandparents, and extended family members) (Kazak, Rourke & Crump, 2003). The medical settings in which children participate are ones that offer rich opportunities for research. Police and emergency medical personnel are also important—but often overlooked—sources of information. Other key systems to involve in research include schools, social support systems, and clergy. Finally, a social ecological perspective on child death necessitates the consideration of cultural context. Little is known about the impact of cultural factors such as race, ethnicity, and religion related to the process of end-of-life care, death, and bereavement.

**Psychological concerns in pediatric end-of-life care** -- Additional research is needed on psychological factors in end-of-life care (e.g., pain, fatigue, and depression) and the interrelationships among these factors in order to inform and improve practice (Berde & Wolfe, 2003). Research is also needed on psychological aspects of limitations in activity and restrictions in social participation and their amelioration and how they relate to quality of life.<sup>15</sup> Increased knowledge of developmental issues in the conception of death by children can guide psychological care during end of life, as can knowledge about how different ethnocultural groups conceive of and relate to illness, death, and the dying process. Research on adherence to treatment (Bearison, 1996; La Greca & Bearman, 2003) offers potential for helping children, families, and treatment teams determine, negotiate, and evaluate the effect of various prescribed treatments. Additional research is also needed to improve understanding of decision making processes when choosing treatment options (both for families and treatment teams), and on how different communication styles or strategies interact with decision making processes and inform or impede those processes.

**Access to care in end-of-life services** – Few data exist to document which patients and families are receiving end-of-life care and what type of care is being provided. Psychological research is needed to improve our understanding of the needs of patients and families, the types of care provided, and the outcomes of services. There are also specific issues related to the funding for these services, such as the importance of documenting the outcomes of end-of-life care and their potential for enhancing patient and family well-being while also containing cost.

**Bereavement** – Bereavement is an extraordinarily complex issue that is influenced by many individual, family, cultural, religious, and societal factors (Stroebe et al., 2001). Additional research is needed to increase our understanding of the process and course of bereavement, particularly as it relates to the cultural dimensions of end-of-life care. This includes improving understanding of the strengths and competencies that individuals, families, and communities exhibit over time as they move through the bereavement process.

**Intervention research related to end of life and bereavement** – Several review papers have now highlighted the lack of empirical support for frequently practiced interventions related to bereavement in general, and questioned the benefits of “grief work” and organized programs of bereavement for families who have lost a child (Bearison, in press a; Bonanno & Kaltman, 1999; Jordan & Neimeyer, 2003; Wortman & Silver, 1989). In fact, there are no evidence-based therapies that focus on either individual or family grieving. In particular, research is needed to increase understanding of how best to match families with appropriate interventions depending on their needs (e.g., families experiencing prior psychological problems that impaired their functioning are likely to need different interventions than those not experiencing such problems) (Bonanno, 2004; Kazak & Noll, 2004).

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<sup>15</sup> Quality of life is directly tied both to activity and participation. The World Health Organization International Classification of Functioning, Disability, and Health (2001) identifies *activity limitations*, which involve disturbed performance of usual age-appropriate activities (such as feeding, dressing, and mobility activities), and *participation restrictions*, which involve disturbed performance of social roles (such as educational and recreational participation).

**Research Recommendations Related to End-of-Life Care for  
Children and Adolescents and Their Families  
Recommendations for APA**

- Develop fact sheets for use by psychologists conducting research on palliative and end-of-life care with all children and adolescents and their families (e.g., information to provide to IRBs; perspectives of families on participating in research, issues related to conducting culturally competent research, etc.);
- Encourage and promote research to increase understanding of how end-of-life-care needs to be tailored for diverse groups of children and adolescents and their families, including those of different cultural and socioeconomic backgrounds, those of different cognitive and physical abilities, women, and sexual minorities;
- Encourage research related to pediatric end-of-life care and bereavement by convening small conferences on relevant research questions and methodologies;
- Establish multi-disciplinary relationships with other professional and scientific groups that work in palliative care; and,
- Develop mechanisms to link psychologists conducting research in these areas and help to disseminate research findings both within and outside of psychology.

**Recommendations for Research Related to Children at the End of life**

- Identify and develop measures for assessing desired outcomes in palliative and end-of-life care with all children and adolescents and their families that are sensitive to the role and impact of ethnic and cultural differences;
- Develop models for understanding relationships among positive outcomes and various treatment and/or care options (e.g., how variables relate to each other, moderating variables, etc.) for all children and adolescents at end of life;
- Prioritize research that increases understanding of how end-of-life-care needs to be tailored for diverse groups of children and adolescents and their families, including those of different cultural and socioeconomic backgrounds, those of different cognitive and physical abilities, women, and sexual minorities;
- Develop innovative methodologies and research designs for addressing research questions (including qualitative approaches) on palliative and end-of-life care for all children and adolescents and on bereavement;
- Evaluate existing palliative and end-of-life programs and services to determine what is and isn't working and why;
- Work to increase knowledge and understanding of the meaning of dying and death for all children and adolescents at all stages of development and for their parents;
- Involve children, parents, and other family members in the research process as participants and informants;
- Include in research protocols questions regarding the negative and positive impact of participating in research studies on palliative and end-of-life care; and,
- Fund and conduct longitudinal studies to better understand the process and variation in how survivors go through end-of-life experiences and move on to bereavement.

## TRAINING

There are two primary and complementary purposes for training psychologists in pediatric end-of-life care. One is to improve clinical care; the other is to promote research. Presently there is very little science to inform the care of dying children; most of what is known is anecdotal and acquired by trial-and-error. Integrating both of these purposes is the goal of creating scientist practitioners who can function both as researchers and clinical practitioners, with each of those roles enhancing the other.

Psychologists who work in palliative care settings often specialize in focusing on the interface between medical and psychological issues. They function as members of multi-disciplinary teams and help clarify the close associations between medical and psychological issues to facilitate better decision making and coping. Competence in these areas has not been succinctly defined; however, a task force of the APA Division of Pediatric Psychology (Division 54; Spirito et al., 2003) has identified the following major areas for training in the field:

- Life span developmental psychology
- Life span developmental psychopathology
- Child, adolescent, and family assessment
- Intervention strategies
- Research methods and systems evaluation
- Professional, ethical, and legal issues pertaining to children, adolescents and families
- Issues of diversity
- The role of multiple disciplines in service delivery systems
- Prevention, family support, and health promotion
- Social issues affecting children, adolescents, and families
- Disease process and medical management

### **Creating a Continuum of Training**

Content on dying and death can be infused into all levels of training in psychology, creating a continuum for learning from the undergraduate to the post-doctoral levels (see Box 2). At the undergraduate level, issues of end-of-life care can be introduced into existing courses, such as developmental psychology or health psychology classes. Similarly, coverage of end-of-life issues can be integrated into graduate level courses that focus on clinical assessment, psychotherapy, developmental psychology, behavioral interventions, ethics, and the like. The difficulties and rewards of working in this area should be addressed at both the undergraduate and graduate levels (e.g., personal motivations for wanting to work with dying children, burnout, etc.). Graduate courses should be developed that focus specifically on palliative care, dying, and death in pediatric psychology. Another venue for training at the graduate level is that of practicum experiences; these should be provided for students who are considering moving into this area of specialization. This could include, for example, having students shadow child life specialists for a semester in a healthcare setting. Other possible practicum settings would include pediatric hospice services (including home-based services) and pediatric rehabilitation centers. Internships, particularly those in pediatric psychology, can incorporate rotations where interns

are in settings where patients die, such as PICUs, NICUs, emergency departments, and pediatric oncology services as well as other relevant settings along the continuum of care (e.g., home health settings). In addition, internship seminars can be offered that focus on topics related to children and end of life.

Although education in pediatric end-of-life issues is appropriate at all levels of training for psychologists, the focal stage of training in end-of-life care is perhaps best conceptualized as clinically-based training during the course of post-doctoral pediatric psychology fellowships. A post-doctoral fellowship is recommended for psychologists who want to establish expertise in end-of-life care with children, and there is a particular need to develop these training opportunities. Training at this level should include clinical supervision of cases concerning end-of-life decisions, and work in multi-disciplinary medical care teams and, if possible, include hands-on training with simulated patients (simulation training) that focuses on issues such as how to convey “bad news” to children and families and how to talk with children about illness and death. At Children’s Hospital Boston, for example, the *Program to Enhance Relational and Communication Skills* (PERCS) uses high-fidelity simulated end-of-life case scenarios with professional actors. The actors provide feedback to the trainees about what it was like to interact with them. In general, as training proceeds stage by stage, it needs to become increasingly more hands-on practice involving other disciplines concerned with end-of-life care.

Training in end-of-life care should not be the sole focus of training during specialized end-of-life post-doctoral fellowships, but rather be integrated as part of the range of activities of pediatric psychologists. Although training in end-of-life care is clearly multi-disciplinary in nature, the best training sites for psychologists are ones that recognize the professional integrity of the practice of psychology. Training sites that provide opportunities to deliver psychological services across medical sub-specialty areas (e.g., oncology, ICU, NICU, etc.) and that involve psychologists as full participants in end-of-life decision making provide particularly good learning opportunities. Although post-doctoral training sites in pediatric psychology typically are tertiary care medical centers, sites might also involve hospices (including home-hospice care) and community-based trauma centers.

### **Box 1: Strategies for Integrating Dying and Death into Training for Psychologists**

#### Undergraduate Level

- Incorporate information about dying and death into existing relevant courses, such as developmental, health, and clinical psychology classes

#### Graduate Level

- Integrate end-of-life issues into existing graduate courses (e.g., clinical assessment, psychotherapy, developmental psychology, behavioral interventions, ethics, etc.)
- Provide cultural competency training that emphasizes interpretive approaches to understanding cultural differences and their implications with respect to end-of-life care
- Offer freestanding courses, such as participatory seminars that present important issues and critical perspectives in palliative care
- Develop practicum opportunities (e.g., in pediatric hospitals working with at-risk groups)

[e.g., oncology, intensive care units, emergency departments], pediatric hospice, etc.)

- Develop approved internship programs in settings where the trainees can gain experience with people who are dying (e.g., hospital-based rotations in pediatric oncology and NICU units)

#### Post-Doctoral Level

- Develop Fellowships that involve applied experience working in interdisciplinary care teams and hands-on simulation training
- Offer relevant Continuing Professional Education courses
- Develop Fellowships to train researchers to conduct research focused on palliative and end-of-life care with children and adolescents and their families

There are now a number of national initiatives focused on end-of-life care for children and adolescents. And, although these initiatives are not specifically geared toward psychology, they provide opportunities for continuing education and professional development for psychologists who wish to specialize in this area. These resources may be especially helpful to lone practitioners and psychologists working in rural areas without ready access to centers providing end-of-life care. The multi-disciplinary Initiative for Pediatric Palliative Care (IPPC), for example, is a collaborative education and a quality improvement effort aimed at enhancing family-centered care for children living with life-threatening conditions. IPPC makes available through the internet a series of six learning modules on topics such as engaging with children and families, analyzing ethical challenges, and responding to suffering and bereavement ([www.ippcweb.org](http://www.ippcweb.org)). For each module, there is a downloadable guide that provides the information needed to facilitate each of the learning activities, including instructions, discussion questions, talking points, case studies, participant handouts, and references. Downloadable PowerPoint® presentations are made available for the learning activities that call for slide presentations. Additional curricula on end-of-life care have been developed by the Children's International Project on Palliative Hospice Services (ChIPPS), End-of-Life Nursing Education (ELNEC), Children's Hospice International Program for All Inclusive Care for Children and their Families (CHI-PACC), and the National Alliance for Children with Life Threatening Conditions.

### **Components of Exemplary Pediatric EOL Training for Psychologists Working in Clinical Settings**

A guiding principle for training psychologists in pediatric end-of-life care is that there is no prescribed orthodox way of dying that is appropriate for every child and family. There is no correct way to die. Instead, the purpose of training is to explore ways to respect and honor what patients and families find is best for them. Psychologists working in palliative care with children and their families need a broad array of skills and content knowledge. The context of death and the dying process must be understood and so it is important that psychologists be familiar with the palliative care literature. Other relevant bodies of research literature with which psychologists working in this area should be familiar include those on: social ecological models, school psychology (e.g., working with children and adolescents in schools), rehabilitation psychology, attachment, decision making, treatment adherence, children's understanding and

conceptions of illness and death, and pediatric pain management. In addition, it is essential to have a working knowledge of the literature on stress and coping. Many clinical models describe coping with death as a logical extension of coping with illness; however, when death is more sudden, it may be more appropriate to invoke models of acute stress and trauma.

Additionally, psychologists working in these settings should be knowledgeable about:

- The demographics and epidemiology of childhood death (e.g., how children are dying, different trajectories of dying, who is dying, etc.);
- The biopsychosocial and biological aspects of dying;
- Cognitive development and its role in understanding circumstances of illness and death
- Critical medical procedures that children may undergo during end-of-life care (e.g., extubation);
- Psychologically sound children’s literature that can help the dying child and grieving family process or understand their feelings; and,
- Informative, credible websites.

It is important to note that the need to be familiar with these areas of knowledge is not necessarily unique to psychologists in healthcare settings, but is relevant to those in community and school settings as well. In light of the central role school plays in children’s lives, it is very important for school psychologists to be familiar with palliative care and end-of-life clinical models to provide care to dying children as well as their surviving classmates.

The skill areas to be addressed in training are organized into the following three general categories:

- 1) Clinical and interpersonal skills,
- 2) Cultural Competence,
- 3) Ethical and professional principles, and
- 4) Organizational knowledge and skills.

Examples of the more specific content areas that are included in these categories are described in the following sections.

### **Clinical and Interpersonal Skills**

It is critical to understand that—in addition to the basic skills that psychologists typically receive in their clinical training—specialized training is essential for those who work in palliative care settings or deal with end-of-life issues for children and their families. From a clinical standpoint, this is a high-stakes field—quite literally dealing with issues of life and death. Although it is not feasible here to define specific clinical competencies, practice in this area must be performed by those with extensive and intensive training and supervision. Although there is presently little available to guide the practitioner, and no standard, empirically evaluated models for providing psychotherapy with children at the end of life and their families, there are a number of areas of knowledge and expertise that can be identified as clearly critical for work in this arena (Sourkes, 1982; 1995).

At a foundational level, it is essential that palliative care psychologists have excellent clinical and psychotherapy skills that facilitate their providing clinical interventions under high stress circumstances and with people experiencing profound anticipated or actual loss. This should include expertise in a broad array of psychotherapeutic models, which can include, for example, individual and family psychotherapy, short- and long-term counseling, play therapy for young children, and cognitive-behavioral techniques. They must know how to intervene in a crisis, have consultation and interpersonal skills, and understand the unique quality of psychotherapy when it is carried out in home visits. Because dying follows a timetable all its own, and the specific circumstances may be unique, therapy with patients at the end of life must be more flexible than traditional service models.

Training programs need to consider ways by which end-of-life care for children (and their families) is more complicated and stressful than it is for adults at end of life. The process of grieving and bereavement in cases involving children is more difficult for families, in part, because the anticipated milestones of life will now never be achieved (e.g., graduating from high school, going off to college, marrying, etc.). Therefore, training needs to consider the immediate needs of children and families, as well as future interventions to support families after their child has died. Attention must be paid to the needs not just of the patient, but to parents, siblings, grandparents, and, at times, other family members and friends (including same-sex partners of biological parents). For example, flexibility is needed as psychologists face the challenge of simultaneously working with multiple family members who may have very divergent agendas and therapeutic needs.

Psychologists participating in end-of-life care for children need the clinical skills to deal with children and their families at times of seemingly unbearable stress and to be able to judge their adequacy to do so (e.g., skills acquired from learning to conduct long-term psychotherapy). Often, the presenting problems in end-of-life care are not as they appear and it requires an exploratory openness and sensitivity to issues that arise. This sensitivity is most likely to be developed in the context of general training in psychotherapy. The needs of children in end-of-life care and their families are highly individualized and complicated and are generally not amenable to problem-focused or behavioral management approaches that are standardized across cases. Yet, at the same time, training has to focus on normative development and not view psychotherapy as dealing solely with psychopathological means of coping with medical trauma. In most cases, it is best for psychologists to consider families who have a child in end-of-life care as normally developing in an abnormal situation (Bearison, 1998).

It is important that training in clinical skills focus on self-reflection about what it is like to provide palliative care to children and their families. Because working with children at end of life and their families is an emotionally demanding process that can evoke feelings of sorrow and frustration in providers, it is vital during training to consider counter-transference issues—which can develop both to parents and to children (Sourkes, 1992).

Psychologists in palliative care settings must have skills to help children and their families through the anticipatory grief process as well as through bereavement after the child has died. This may include an array of verbal strategies as well as specific interventions aimed at helping

others to remember children’s lives, such as through writing, music, art work, memory boxes, or making videos. Child life specialists are particularly well trained in these interventions.

Another area of training has to do with the particular competencies that psychologists need in areas of interpersonal engagement, communication, and problem solving; competencies that they can share with other members of pediatric palliative care teams. Knowing how to communicate “bad news” to families and promote frank discourse among patients, families, and medical staff is a central part of psychological training in end-of-life care. Discussing serious diagnoses, impending death, and death represent regular challenges in health care settings, and psychologists trained in these skills who can facilitate and model such discussions are highly valued. Training in this area also includes knowing when and how to ask questions prior to giving news and advice so as to assess and acknowledge what the family already knows about their child’s condition. Skills in assessing and preventing potentially conflictual situations and de-escalating high-conflict situations, when they occur, are also important for psychologists to master.

Health care clinicians are generally not well-trained or confident in end-of-life communication (Eggle, Afonso, Rojas, Baker, Cardozo, L & Robertson, 1997; Roter, Larson, Fischer, Arnold, & Tulsky, 2000; Sahler, Frager, Levetown, Cohn, & Lipson, 2000). Communication and relational skills are underemphasized and undervalued in training compared to technical skills; as a result, clinicians are often ill-equipped to conduct end-of-life conversations. Most physicians report learning about end-of-life care by trial and error (Hilden, Emanuel, Fairclough, Link, Foley, Clarridge, Schnipper, & Mayer, 2001). Unfortunately, such unstructured and unguided learning by experience can put patients, families, and trainees at risk of much preventable suffering. Often, clinicians report anxiety and dread when discussing serious diagnoses, impending death, and death (Ahrens & Hart, 1997; Buckman, 1984; Hilden et al., 2001). Underlying emotional issues that may compromise the clinician’s ability to communicate include fear of being blamed, fear of the unknown and untaught, fear of unleashing an uncontrollable reaction, fear of expressing emotion, fear of not knowing all the answers; and personal fear of dying and death (Bearison, in press b; Buckman, 1984).

A thorough understanding of the issues, challenges, and recommendations for best practice in end-of-life communication are recommended for psychologists who practice in the area and who may wish to expand their role beyond provision of direct clinical service (Buckman, 1984; Curtis, Engelberg, Wenrich, Nielsen, Shannon, Treece, Tonelli, Patrick, Robins, McGrath, & Rubenfeld, 2002; Girgis & Sanson-Fisher, 1995; Larson & Tobin, 2000; von Guten et al., 2000; Zoppi & Epstein, 2002). Familiarity with available “breaking bad news” and end-of-life curricula that have been developed for health-care clinicians is also recommended including Buckman’s 6-step protocol (1992), the ABCDE model (Rabow & McPhee, 1999), the curriculum entitled Education for Physicians in End-of-life Care (EPEC) (Emanuel, vonGuten & Ferris, 1999; vonGuten et al., 2000), and the curriculum developed in conjunction with the Initiatives in Pediatric Palliative Care (IPPC) (Solomon, Dokken, Fleischman, Heller, Levetown, Rushton, Sellers, & Truog, 2002; Browning, 2003).

### **Cultural Competence**

Psychologists need to be culturally sensitive to how families cope with end-of-life issues. Much of what we consider to be fairly predictable in clinical care dramatically changes as one integrates divergent cultural practices into the palliative care setting. There can be a great deal of diversity with regard to views of death, roles within the family, grieving, and so forth, even within ethnocultural groups. For example, how do different cultures view the process of death, and the death of a child in particular? How is the role of the family, and of individual family members, seen? What kinds of decision making processes are viewed as appropriate? Although responses to childhood death are poorly defined, the cultural context is central in helping to define positive outcomes. Although the research bases for addressing these concerns is lacking (Koenig and Davies, 2002), as the demographic composition of the United States continues to change, the need for taking cultural factors into account will expand exponentially. It is important to understand these issues—including having an awareness of the biases inherent in one’s own culture—in order to provide culturally competent care and in order to conduct research.

Cultural competency training is more likely to be effective if it emphasizes an interpretive approach to understanding cultural differences (Koenig & Davies, 2003). Rather than simply providing information about the attitudes and practices of different groups, these approaches use a more sophisticated concept of culture that considers such issues as racism, socioeconomic status, and the ways in which such issues interrelate with ethnocultural status. Case-based approaches are often used that emphasize interpreting the importance of cultural differences for a particular child and family in the context of these kinds of social and historical factors.

### **Ethical and Professional Principles**

Psychologists working in pediatric palliative care must be well-grounded in the ethical codes related to psychological practice. As members of multi-disciplinary care teams, it is important that they understand the need to recognize the limits and boundaries of their own competence, especially in situations where conflicts may arise between the family and the care team.

Training should help psychologists understand the potential for ethical challenges as various cultures interface, and how to intervene when a family’s cultural practices conflict with institutional policies. Psychologists must be attuned to these differences and know how to utilize available resources to address conflict and facilitate coping.

Another component of training is on promoting leadership qualities and educating psychologists about the qualities and skills that they need to be in leadership positions in this field, including understanding how to recognize what kinds of institutions are open to and supportive of their efforts.

### **Organizational Knowledge and Skills**

An important task for training psychologists to work in palliative care settings is to provide them with the skills and opportunities to learn about the culture of health care settings. For example,

spending time on a regular basis with members of a child life department—who focus on the interface of normal developmental processes and the demands of illness and treatment—is a good strategy for doctoral students to learn about what happens in hospitals and to get some hands-on experience. One of the best venues for training psychologists to appreciate the multi-disciplinary culture of pediatric end-of-life care and the contributions and roles of other specialties is to have them participate in multi-disciplinary teaching rounds, including those conducted at the bed-side and Mortality and Morbidity (M &M) meetings. During training, it is important for psychologists to learn how to function as a member of a team and to learn about the contributions that other disciplines have to make. At the same time, such participation and teamwork provides opportunities for psychologists to educate those in other disciplines about the contributions and roles of psychologists.

Psychologists engaged in end-of-life care also need to know the language of medicine and have a basic working knowledge of medical issues (including the causes of death and the dying process) and medical procedures (e.g., intubation, bone marrow transplant, pain management, etc.). It is also important that they be knowledgeable about home and community care of persons with disabilities, including rehabilitation services and procedures (e.g., adaptive techniques and assistive technology for self-care, environmental control, and social participation).

### **Training Psychologists to Conduct Research in Pediatric End-Of-Life Care**

As discussed in the previous section on research, training of research psychologists should include information on how to present end-of-life studies to hospital IRBs. End-of-life research studies have the potential to raise concerns among hospital administrators who worry about about institutional culpability together with their perceived need to protect (or over-protect) grieving families whose children are dying or have died.

Psychologists conducting research on end-of-life care need to understand the inevitable challenges involved in getting families to consent to participate in research studies dealing with end-of-life issues. For example, some families will proclaim “I’m going through living hell, but if there’s anything that I can do to improve another family’s plight in the future, I will do it.” But other families will state that, “This is a terribly painful and private experience and I don’t want anybody coming in to talk to me or my kid about it.” Such differences in attitudes among families will inevitably bias the sample researchers are trying to capture.

Psychologists should be trained to understand how, when, and why some kinds of research questions call for more qualitative than quantitative kinds of measures and how one approach relates and advances the other.

### **Training Recommendations Related to End-of-Life Care for Children and Adolescents and Their Families**

### **Recommendations for APA**

- Conduct a national survey to assess the amount and type of educational experiences that undergraduate and graduate programs in psychology offer in the area of dying, death, and bereavement. Specifically, the survey should assess whether existing coursework includes the topic of childhood death, children’s developmental understanding of death, and the special circumstances related to death in childhood, as well as the degree to which programs address issues related to working with diverse groups.
- Conduct a survey of leading undergraduate and graduate level psychology textbooks and psychology encyclopedias to determine the amount of text and attention devoted to childhood death and end-of-life issues and the content covered. If, as expected, there is a paucity of information found on these topics, urge authors and editors to remedy the situation.
- Develop a faculty guide for integrating end-of-life issues, including pediatric end-of-life issues, into psychology course curricula at both undergraduate and graduate levels. The faculty guide should provide the demographics of death and the rationale for including end-of-life issues in psychology courses, outline key content in end-of-life clinical assessment and care, and discuss strategies for integrating information into courses that are required and commonly taught (e.g., developmental psychology, clinical assessment, psychotherapy, ethics).
- Develop a faculty guide for developing and supervising undergraduate, graduate, and clinical internship level practicum experiences in end-of-life pediatric care. The faculty guide should provide a listing and description of potential practicum sites and experiences, examples of interactive and simulated learning opportunities, and discussion topics to foster self-awareness and processing of students’ affective responses to difficult loss and end-of-life situations. Potential practicum sites might include: hospitals; community and home-based hospice organizations; and pediatric rehabilitation settings.
- Develop a faculty guide for training at the graduate and post-graduate levels on how to provide culturally competent end-of-life care to diverse groups of children and adolescents and their families. The guide should focus on using interpretive approaches to understanding group differences and include model case studies.
- Develop a model and curriculum materials for general post-doctoral fellowships in pediatric psychology to incorporate case-based pediatric palliative care, pain management, communication and relational skills, rehabilitation psychology, use of ritual, ethics, and issues related to working with individuals of diverse groups in end-of-life care. Clinical work at the fellowship level should include settings where children die, including neonatal and pediatric intensive care units, emergency departments, oncology services, and home settings.
- Produce and disseminate a case book with examples of pediatric end-of-life cases to illustrate the range, nature, and unique characteristics of death in childhood. Emphasize

the developmental, family systems, societal, decision making, ethical, and cultural and socioeconomic diversity issues that bear on the delivery of care to dying children and their families, and present models of care. The case book should include examples that are representative of the diagnoses and trajectories of dying that children experience including: short gestation; unintentional injuries; congenital anomalies; malignant neoplasms; heart disease; and suicide and homicide. The case book could serve as an educational tool for psychologists, helping them to understand the complexities central to caring for dying children and their families and to working as a member of a multidisciplinary team.

- Develop and deliver a continuing education program for practicing psychologists on pediatric palliative and end-of-life care. Offer the program on-line through the APA website and on-site at the national APA Convention, as well as to state and provincial psychological associations. Content for the CE program should incorporate the essential knowledge, skill, and interpersonal areas identified by the Institute of Medicine to prepare health care professionals to provide palliative, end-of-life, and bereavement care to children and families.
- Develop a directory of psychologists interested and involved in pediatric end-of-life issues, specifying the nature of their activities in education, research, clinical practice, and policy. This might be accomplished by adding an end-of-life interest code to the standardized APA membership questionnaire. This directory could be included in the APA website and would serve to identify potential clinical referrals and consultants in the field, to foster networking and collaboration, and to establish end of life as an area of specialty among psychologists.
- Develop a directory on the APA website that provides key pediatric end-of-life documents and references, links to other relevant end-of-life care websites and educational curricula, and the names and contact information of psychologists who are experts in the area of pediatric end-of-life care.
- Given the multidisciplinary nature of pediatric end-of-life care, APA is encouraged to develop collaborative partnerships with the professional organizations representing physicians, nurses, social workers, child life specialist, and chaplains who care for dying children and their families. Jointly sponsored educational opportunities and reciprocity of continuing education credits in the end-of-life field would accelerate the training of psychologists in the area and forge important professional collaboration and relationships.

## **POLICY**

Policies that impact the care and treatment of children and adolescents with life-limiting conditions get made at the federal, state, and local levels (including at the institutional and programmatic levels). These include policies that dictate what kinds of services may be offered to these children and their families and how they will be paid for, what kinds of related research might be funded, whether these issues are a focus of training dollars, and more. In this section,

recent initiatives to address the palliative care needs of children and their families are described and a number of activities that APA might undertake to influence policy are identified.<sup>16</sup>

A key area for federal advocacy has to do with funding of services through Medicaid, which is the source of health coverage for approximately one fifth of children (IOM, 2003). Although hospice care is covered as a service under the Medicaid program if it is included in the state Medicaid plan (all but six states cover this service), in many States the requirements to qualify for hospice services are particularly problematic when it comes to providing care to children and adolescents (IOM, 2003). First, hospice care is limited to patients whose life expectancy has been certified to be six months or less. This creates difficulty in the case of children because their life expectancy is often uncertain and unpredictable, in part because they tend to be more resilient than adults and are sometimes able to recover. In fact, a child with a life threatening illness may live days or years depending on the condition. Additionally, current limitations require that hospice care be supported *only* if all curative or life-prolonging options have been abandoned, a particularly troublesome requirement in the case of children that places parents in a nearly impossible position.

Known as the Children’s Compassionate Care Act of 2003 in the Senate (S. 1629) and the Pediatric Palliative Care Act of 2003 in the House (H.R. 3127), legislation was introduced into the 108<sup>th</sup> Congress that would, among other things, support Medicare and private sector palliative care demonstrations. These proposed demonstrations would lift the current eligibility barriers to access to hospice services for children and they would require coordination and continuity of care across inpatient, home, and community-based settings, regardless of ability to pay.

Although the legislation did not pass during the 108<sup>th</sup> Congress, it contained a number of key elements that can provide a framework for advocacy on these issues. The proposed legislation would:

- Provide multi-disciplinary training in pediatric palliative care and related services;
- Implement or expand pediatric care programs for children with life-threatening conditions;
- Expand the number of physicians, nurses, mental health professionals, and specialists with pediatric palliative clinical training and research experience;
- Enhance pediatric palliative care and care for children with life-threatening conditions in general or pediatric or family practice residency training programs through the development of model programs;
- Fund research in pediatric pain and symptom management that will utilize existing facilities of the National Institutes of Health; and,
- Provide for Medicare and private sector pediatric palliative care demonstration projects.

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<sup>16</sup> The Institute of Medicine report on *When Children Die: Improving Palliative and End-of-Life Care for Children and Their Families* (IOM, 2003) provides an extensive analysis of relevant policy issues. The reader is referred to this volume, available at [www.nap.edu](http://www.nap.edu), for a more in-depth review of the issues.

Pediatric palliative care services and research grants outlined in the proposed legislation would be designated toward the development and implementation of clinical practice guidelines and protocols for pediatric, palliative, end-of-life and bereavement care. The proposed grants would also provide consultative services to health care providers to aid in the development of pediatric palliative care programs.

### **Recommendations for APA Related to End-of-Life Care for Children and Adolescents and Their Families**

- Work independently and in coalition with other health and mental health professionals, consumers, advocates, and coalitions (e.g., the Last Acts Partnership) to educate policy makers (including key congressional staff of relevant committees) and federal agency officials about the psychosocial aspects of end-of-life care, including the role psychologists play in dealing with children, youth, and families in caring for all children and adolescents who have a terminal illness and the need for changes in payment and reimbursement systems.
- Support and advocate for legislation that can help to make the public and private health and mental health systems more flexible for meeting the health and mental health needs of all children and adolescents with terminal illness and their families.
- Support and advocate for legislative and regulatory changes that assure and protect access of sexual minority parents and their partners to their children at end of life, and their involvement in decision-making in palliative and end-of-life care.
- Work to assure that legislation that addresses the palliative care and end-of-life needs of children and adolescents with life-limiting conditions and their families includes support for psychosocial and other services provided by psychologists.
- Advocate for funding for research and training fellowships to support the training of psychologists to prepare them to work in palliative and end-of-life care with children and adolescents and their families, including those of diverse ethnic, cultural, and socioeconomic backgrounds, cognitive and physical abilities, and sexual orientations.
- Advocate for funding to support research on palliative and end-of-life care for children and adolescents and their families, including outcomes research.
- Advocate for funding to support research to increase understanding of issues related to end-of-life care for diverse groups of children and adolescents and their families, including those of diverse ethnic, cultural, and socioeconomic backgrounds, cognitive and physical abilities, and sexual orientations.
- Advocate for funding to support services that address the particular needs of diverse populations of children and adolescents and their families, including those of different ethnic, cultural, and socioeconomic backgrounds, cognitive and physical abilities, and sexual orientations.

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## APPENDIX A

### **Adolescent Decision Making at the End of Life: Legal, Ethical, and Clinical Considerations**

Gary A. Walco, PhD

There is fairly universal agreement that there needs to be respect for the individual when it comes to making decisions about medical care, including at the end of life. From a legal, ethical, and clinical perspective, getting meaningful input from competent individuals is at the core of consent to treatment, as well as decisions to withhold or withdraw various treatments, including those that may hasten death. As long as the patient and care provider agree on these issues, there is little or no conflict and care may be rendered in a way that is deemed appropriate by all parties involved.

The situation becomes significantly more complicated, however, when various elements of the above equation are changed. What if the care provider and patient do not agree on the propriety or benefit of rendering, not rendering, or withdrawing certain interventions? What if there is some question about the competence of individuals to make judgments on their own behalf? What happens when somebody else has the authority to make decisions for the individual, such as a minor, but there is not agreement among the care provider, the person legally responsible for decision making, and the child patient? At these times, the usual practices related to medical decision making may be tested to the extreme.

#### **Legal Parameters**

Section One of the Fourteenth Amendment of the U.S. Constitution states, “No State shall make or enforce any law which shall abridge the privileges or immunities of citizens of the United States; nor shall any State deprive any person of life, liberty, or property, without due process of law; nor deny to any person within its jurisdiction the equal protection of the laws.” In 1914, Justice Cardozo explicitly commented on the application of this principle to health care, “Every human being of adult years and sound mind has the right to determine what shall be done with his own body; and a surgeon who performs an operation without the patient's consent commits an assault, for which he is liable in damages...” (Schloendorff v. Society of New York Hospital, 1914, p. 1). In the Supreme Court decision on the Cruzan case (Cruzan v. Director, Missouri Department of Health, 1990), Justice Rehnquist, writing for the majority, stated “The logical corollary of the doctrine of informed consent is that the patient generally possesses the right not to consent, that is, to refuse treatment” (p. 5). He also noted that with increasing medical technology, sustaining life beyond what might occur naturally has become more commonplace, and thus conflicts regarding the refusal or withdrawal of treatment would likely arise with increasing frequency.

These principles have been tried and upheld repeatedly with regard to “adult” patients of “sound mind.” The issues become much more difficult, however, when those conditions are not met. Our interest here lies in the former, individuals who have not yet reached the age of majority. A U.S. Supreme Court decision in 1944 made clear the doctrine that “the custody, care, and nurture of the child reside first with the parents...” (Prince v. Massachusetts, 1944,

p. 3), a notion clearly applied to consenting (or not) for medical treatment (Traugott & Alpers, 1997). Furthermore, the U.S. Supreme Court, in addressing cases focusing on adolescent abortion decisions and psychiatric evaluation, asserted that adolescents have limited autonomy for “making life’s major decisions” due to immaturity and vulnerability. Taking those rulings at face value, parents or legal guardians would be responsible for providing or withholding consent around all medical interventions until the individual is 18 years of age.

Circumstances have been recognized, however, in which minors may have the legal right to make their own medical decisions. This includes legally emancipated minor status, afforded as a function of marriage, pregnancy, parenthood, or military service. There is also mature minor status, providing legal protection to a minor’s medical decision making based on evidence of maturity (as shown by ability, experience, education, training, conduct, and demeanor) to make such decisions. There are no specifically defined criteria for evidence of maturity, however, and there is variability both state to state and case by case.<sup>17</sup> It should also be appreciated that if a physician deems a patient to be a mature minor, there is an exposure to liability if that judgment is later questioned. Finally, various states have gone further in affirming independent adolescent medical decision making, enabling autonomous consent to treatment for substance abuse, sexually transmitted diseases, pregnancy, and, in some cases, psychiatric problems (Weir & Peters, 1997). However, statutes pertaining to refusing treatment, such as at the end of life, do not exist.

For adults, statutes that have provided for the use of advanced directives, which stipulate specific practices regarding care or naming a proxy, have been quite helpful in working through these issues (Weir & Peters, 1997). Although the American Medical Association (1992, 1996) American Academy of Pediatrics (1995) recommends that physicians incorporate the wishes of mature adolescents, and the Group for the Advancement of Psychiatry (1989) cite data supporting the ability of most individuals over the age of 14 years to participate meaningfully in an informed consent process, state advanced directive legislation rarely recognizes a living will or power of attorney executed by a minor (Hartman, 2004). In the interim, by implementing models of palliative care, where communication is enhanced early on, there is likely less risk of issues polarizing and becoming adversarial (Hartman, 2004), and advanced directives for minors, especially if included in the pediatric consent process, may facilitate this process (Weir & Peters, 1997).

### **Ethical Considerations**

The central ethical principle pertaining to decision making in pediatrics, including end-of-life issues, is what is in the best interests of the child (American Academy of Pediatrics Committee on Bioethics, 1994). Critical questions emerge when trying to determine the “best interests of the

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<sup>17</sup> In Great Britain, the “Gillick competence,” derived from a House of Lords decision, is often cited (Gillick v. Norfolk and Wisbech Area Health Authority, 1985). An individual under the age of 16 years may be able to give consent for treatment if “capable of understanding what is proposed, and of expressing his or her own wishes.” Even with such precedent, however, the law does not specify whether children must *actually* understand the issues involved or if they are simply deemed *capable* of understanding. Decisions are still made for specific treatments and for individuals on case by case basis.

child.” Smith (1998) focuses on informed consent as the cornerstone of ethical decision making for minors, highlighting six key components of disclosure: (1) diagnosis and supporting information, tests, or alternatives, (2) nature and purpose of the proposed treatment, (3) risks of the proposed treatment and the probability and severity of those risks, (4) the probability of success from the treatment, (5) alternative treatments, and (6) prognosis, if the treatment is declined. Included are decisions related to the denial of care, withdrawal of care, and medical futility. According to Smith, patients and families should be privy to all of such information and minors should be involved in the decision making process to the degree possible. Hospital biomedical ethics committees should be consulted when indicated.

The basic ethical dilemma may well persist, however, when the views of patients, their families, and their care providers are at odds. Although Traugott and Alpers (1997) assert that legal confrontations should be avoided whenever possible, in applying the principle of best interests of the child, they find that: “When an adolescent makes an informed refusal of interventions, respecting the patient’s liberty coincides with acting in his or her best interests” (p. 925). Weir and Peters (1997) take a firmer stand, “. . . . most neurologically normal adolescents have the capacity to make decisions about their health care and in increasing willingness by physicians and parents to affirm them in doing so” (p. 29). It is striking how different these views are to those presented in the Supreme Court’s basic stance, highlighting the distinction between legal and ethical parameters.

If the aim of biomedical ethics is conflict resolution, a critical first step is to identify and define specific sources of conflict. There are three basic perspectives to consider: those of the adolescent patient, the parents, and the medical care providers. When any of these three parties is not in sync with the others in decision making, ethical dilemmas may emerge. The ultimate question is who decides what is in the child’s best interests.

Disagreements among parents and care providers are governed by many of the same principles as disagreements between care providers and patients at the age of majority; in both instances these are the parties responsible for providing consent to treatment. Exceptions arise when parents make decisions that medical providers consider not to be in the best interests of the child. A classic example is the case of parents who are Jehovah’s Witnesses, who typically oppose having blood transfusions, even when deemed life-saving. In these cases, judicial hearings often lead to parental authority being overruled (*parens patriae*), so that the transfusion may be administered on a one-time basis (Traugott & Alpers, 1997). An additional question concerns the role of the child in these circumstances. What if the child shares the parents’ religious values and opposes the transfusion? If he or she is recognized as a competent minor, his or her opinions should be respected. However, when this issue was tried in New York State, the court refused to support a nearly 18 year old boy with cancer and transfusions were mandated according to the wishes of the physician (Application of Long Island Jewish Medical Center, 1990). Central here are the criteria for defining a “mature minor” and how they may be applied.

Unique difficulties arise when the adolescent patient has discrepant views from those of the care providers and parents, especially when the adolescent refuses therapy. A case that was in the press in 1994 involved a 16- year- old boy who ran away from home because he refused to continue on maintenance doses of chemotherapy for Hodgkin disease (once he had been found to

be disease free),. He refused although both his physicians and parents thought it was in his best interests (cited in Traugott & Alpers, 1997). Is it ethical to “capture’ the boy and restrain him in order to administer chemotherapy? Should his opinion be ignored?

Finally, consider a situation in which the parent’s view diverges from the adolescent patient’s view and the physician’s view. A 17- year- old girl with advanced leukemia made it clear to providers that she would prefer comfort care instead of further aggressive chemotherapy regimens, and clearly understood that she would die. However, her mother refused to honor her daughter’s wishes, and chose to pursue experimental treatments in an attempt to prolong life. The mother denied consent for comfort care, including aggressive pain management, for fear that this might compromise her daughter’s response to possible disease modifying agents. Should narcotics be reduced in response to parental wishes? Should the child be given chemotherapy, even though she made it clear she does not want it? Should she be enrolled in a trial of an experimental agent, even though it appears she does not want to give assent? If she is deemed to be an emancipated or mature minor, her opinions would need to be heard.

### **The Development of Decision making**

Adolescence is a time marked by a number of important developmental shifts, one of which is questioning the decision making authority of others, particularly parents (Mann, Harmoni, & Power, 1989). Decision making involves many cognitive processes, including information search and processing, problem-solving, judgment, learning, and memory, as well as social and motivational factors. Mann and colleagues list nine factors (‘C’s’) related to **competent** decision making: (1) willingness to make a **choice**, including the sense of individuality to go beyond conformity; (2) **comprehension** that a decision process is unfolding; (3) **creative** problem solving; (4) **compromise**, including the recognition that certain goals may not be attained; (5) **consequentiality**, the recognition that certain decisions likely will lead to certain consequences; (6) **correctness**, with regard to the logical processing and validity of information; (7) assessing the **credibility** of information being used to reach a decision; (8) **consistency** in stances across time and circumstances; and (9) **commitment** to a decision once it is made. It is interesting to note that if one were to score adult decision makers on each of these nine factors, it is unlikely that many would reach a standard sufficient to be considered a “competent minor.”

Byrnes (2002) summarized decision making as having four steps: (1) setting a goal, including optimally adaptive goals and means of accommodating competing goals; (2) compiling options for producing that goal, including overcoming obstacles to acquire needed information, seeking advice; (3) rank ordering options, analyzing pros and cons; and (4) selecting the highest ranked alternative. This is rarely a simple stepwise process, but more one that integrates components in a dynamic process. However, just because someone has the skills to make good decisions does not always imply that he or she will make good decisions. Factors related to development and individual differences must be taken into account during assessment, but these models are useful in determining the competence of a minor to make competent decisions.

### Clinical Perspectives

We might assume certain premises when considering end-of-life palliative care to adolescents (George & Hutton, 2003). A central issue is respecting the adolescents' emerging autonomy (Kuther, 2003; McCabe, 1996). Thus, one would ideally want to help them master a situation as well as possible so that they can contribute in a meaningful way to decision making. A second concern involves the duties and responsibilities of parents. Parents are "legally responsible" for their children's well-being, and assumed to be motivated to do what is best for their child. They are also often coping with substantial emotional issues of their own, struggling with what they perceive to be best for themselves and what may be perceived to be best for their child or the child's siblings. Finally, the perspectives of the care providers are an important in regard to the principle of *in loco parentis*, where the aim is to represent the perceived best interests of the child.

When faced with conflict between the views of the adolescent, parents, and medical care providers, the legal issues set general parameters. For example, one cannot comply with the wishes of a minor to the exclusion of parental wishes unless that minor is either emancipated or deemed to be mature. Without passing that basic test, clinical interventions should focus on helping the adolescent adapt to the circumstance, since legally care could not be rendered otherwise.

Ethical decisions focus on what is in the best interest of the child, but that is not always clear and perspective matters greatly. In the case presented above of the 17- year- old girl with advanced leukemia, it may seem perfectly reasonable to comply with her wishes, providing palliative care only and not subject her to experimental chemotherapy agents. A biomedical ethics committee, in fact, agreed that she was a mature minor and that her decisions should be respected and upheld. But as the young woman herself pointed out, doing so would irrevocably alienate her from her mother, which was unacceptable to her in her few weeks of life remaining. Clearly legal, ethical, and clinical parameters are not always in perfect alignment.

There are very few studies on optimal paradigms or strategies to address autonomy and decision making among adolescents in health care in general, much less at the end of life. George and Hutton (2003) focus on the normalcy of adolescence, the importance of being truthful with adolescents, maintaining their confidentiality, and highlighting positive communication. McCabe (1996) describes a continuum of involvement for children and adolescents in the medical consent process. The child's cognitive and social development are considered along with child specific, family, and situational factors in order to ascertain the extent of a child's involvement at any point in time.

Hinds et al. (2001) described three inter-institutional studies from which they derived specific recommendations for assisting with end- of- life decisions in pediatric oncology. There are three sets of recommendations, one for assisting parents, one for assisting adolescent patients, and one for health care team members assisting each other with such decisions. The model focuses on issues associated with stages of the illness (diagnosis, deterioration of the patient's condition or situation, end of life, and ongoing support), with issues in each stage building on the former. A common theme throughout is the importance of communication among all parties. .

Adolescents' levels of autonomy in decision making clearly have a significant effect on their own psycho-social adjustment. In addition, it is clear that parents and significant others enter into a transactional relationship, as they influence and are greatly affected by these decisions. Kuther (2003) further points out that physicians must walk a fine line between respect for minors' autonomy, respect for parental rights, and the legal standards imposed. Based on this comprehensive picture, the roles of psychologists may be broad and varied. Clearly, facilitating communication and resolving conflicts are central, but one must take into account the well-being of the adolescent patient, parents, and family members, and the integrity of providers and the medical system as well.

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**APPENDIX B – COMMON MEDICAL ABBREVIATIONS AND TERMS ASSOCIATED  
WITH END-OF-LIFE CARE**

<b>Terms and Abbreviations</b>	<b>Meaning</b>	<b>Significance</b>
ABC	Airway, Breathing and Circulation	Prioritized concerns for performing resuscitation
Airway	Synecdoche for mouth, pharynx, larynx, trachea and bronchi	Passageway necessary for breathing
ANC	Absolute Neutrophil Count (Low < 500)	A measurement of immune capability and bone marrow function
AND	Allow Natural Death	An alternative term for DNR
Apnea challenge	A test for the presence of spontaneous respiration	An assessment of brain death
ARDS	Acute or Adult Respiratory Distress Syndrome	A common end point of pulmonary or systemic insult ∴ high mortality
Blown Pupil	Non-reactive dilated pupil	Indicative of herniation
CPAP	Continuous Positive Airway Pressure	Support for the inability to maintain a patent airway
CPR	Cardiopulmonary Resuscitation	Securing airway, ventilation and chest compressions
Death rattle	Upper airway noise (EOL phenomenon)	Created by the inability to clear secretions
DNR	Do Not Resuscitate	Medical directive order
ECMO	Extra-Corporeal Membrane Oxygenation	Technique to supplement severely impaired cardiopulmonary function
ESLD	End Stage Liver Disease, possible EOL phenomenon	Associated with ascites, coagulopathy, jaundice and altered mental status
ESRD	End Stage Renal Disease, possible EOL phenomenon (progressive vs. acquired)	Function impaired by innate disorder, shock, or medications ∴ dialysis
EVD	External Ventricular Drain	A device to remove excess CSF and decrease ICP
GCS	Glasgow Coma Scale (0-15)	A score < 8 associated with high mortality
Herniation	Extruding of Cerebellum via Foramen Magnum	Brainstem compression, potentially lethal event
ICP	Intracranial Pressure (normally 5-15)	A measurement to assess the risk of herniation

In-born Errors of Metabolism	Genetic disorders lacking essential enzyme(s) or substrate	Potentially lethal disorders presenting in childhood
Intubation (endotracheal)	Laryngoscopy and tube insertion to secure the airway	In preparation for assisted ventilation and prevention of aspiration
Inotropic agents	Cardiovascular supportive medications: dopamine, dobutamine, isoproterenol, milrinone, amrinone	Indicative of significant cardiovascular compromise used for shock, and surgery cardiomyopathy
IVH	Intraventricular Hemorrhage (Grade I-IV)	Possible complication of prematurity
Meconium	Intestinal contents (first stool) with can be inhaled at or before birth	Aspiration can cause RDS and severe pulmonary compromise
NEC	Necrotizing Enterocolitis	Neonatal bowels disease require surgical resection
Opportunistic Infections	Atypical infections of immunosuppression	Seen in AIDS and Oncology patients, difficult to eradicate
PCA	Patient Controlled Analgesia (pump)	Opioid self-delivery system frequently used at EOL
PCEA	Patient Controlled Epidural Analgesia	Local and opioid delivery system to epidural space
PEEP	Positive End Expiratory Pressure (mechanical ventilation setting)	Increased (>5) when O2 delivery is compromised
Primitive reflexes	Vestigial reflexes suppressed by normal neurological function	Elicited in the presence of significant brain damage
Protective reflexes	Such as; corneal and gag	Absence indicative of brain death
RDS	Respiratory Distress Syndrome (neonatal lung disease)	Secondary to prematurity, infection and aspiration
Shock	Cardiovascular instability (life threatening)	Common end point of different etiologies including hemorrhage, sepsis and anaphylaxis
Sepsis	Systemic infection (life threatening)	Seen with virulent microbes and in neonates and the immunocompromised
Tamponade	Blood or fluid filling the pericardium	Dramatic decrease in cardiac function requiring immediate intervention
VPS	Ventricular-peritoneal shunt	Device surgically placed to drain CSF