Key Factors Affecting Dying Children and Their Families

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ABSTRACT

The death of a child alters the life and health of others immediately and for the rest of their lives. How a child dies influences parents’ abilities to continue their role functions as well as siblings’ abilities to make and maintain friendships, and may be the basis for health care providers’ decisions to exit direct care roles. Thus, facilitating a “good death”—an obvious care priority for all involved with the dying child—ought also to be a priority for the health of bereaved families and affected health care providers. Making this a care priority is complicated by a serious lack of data, as details of the last hours or weeks of a dying child or adolescent’s life are largely unknown. The purpose of this paper is to identify key factors that affect the course of dying children and adolescents and that of their bereaved survivors, and to link those key factors to needed research that could produce clinically relevant findings to improve the care of these patients. Key factors described here include suffering (physical, psychological, and spiritual), communication, decision making, prognostic ambiguities, ability of the seriously ill child to give assent to research participation, and educational preparation of health care providers to give competent end-of-life care.
nually around the world is complicated by a serious lack of data, as details of the last hours or weeks of a dying child’s or adolescent’s life are largely unknown; no doubt the ways to facilitate a good death are embedded in those details. Documented characteristics of a child’s dying could be the basis of a population-based, interdisciplinary, pediatric end-of-life care model. The purpose of this paper is to identify key factors that affect the course of dying children and adolescents and that of their bereaved survivors, and to link those key factors to needed research that could produce clinically relevant findings to improve the care of these patients.

**SUFFERING AT END OF LIFE**

*Physical suffering*

Parents and health care providers have reported lingering anguish when the dying child experienced suffering secondary to troubling symptoms. The symptoms that children experience while dying likely differ by cause, type, and intensity of previous treatment, and available care resources. Children with complex chronic conditions die differently (longer hospital stays, more symptoms, more procedures especially during the final 3 months of life) than do children who do not have such conditions. Children with different types of complex chronic conditions have symptom patterns that differ by condition with some children experiencing two to eight troubling symptoms while dying. Available symptom reports tend to be from a single site or a single geographic region and thus do not constitute population-based research findings. Documenting the prevalence, intensity, and variation in symptom patterns by type of death will provide the basis for prioritizing troubling symptoms for interventions designed to prevent or diminish the symptoms and the suffering caused by them.

Designing interventions intended to diminish symptoms and related suffering presumes the ability to measure the symptom characteristics. The remarkable advances in the availability of psychometrically sound and developmentally appropriate instruments to measure the health status of well children and adolescents has not translated into such instruments for use with terminally ill children or adolescents. Recent reviews on this issue concluded that no instrument yet existed for most symptoms experienced by a dying child. A concentrated focus is needed on assessing existing pediatric instruments for their clinical validity when used with terminally ill children and on developing and testing instrumentation where none now exists.

Certain, there are data from terminally ill adults regarding symptom profiles and interventions but such research findings may not accurately generalize to terminally ill children. Although scant, there are data that indicate children and adolescents receiving care in a pediatric intensive care unit died more quickly after life-sustaining treatment was withdrawn (86% within the hour) than did adults who lived a mean of 4 hours after such treatment was withdrawn. Children receiving end-of-life care that includes an experimental agent have also been found to have biological responses that differ from those of adults receiving the same agent. Basing pediatric end-of-life care on the symptoms and experiences of adults is a tenuous approach and could have catastrophic implications for defining and providing quality care for dying children and adolescents.

*Psychological and spiritual suffering*

The psychological and spiritual impact of a child’s dying is not restricted to the patient and thus requires the extension of care efforts to include parents, siblings, extended family members, peers, and health care providers. The care necessary to address the psychological and spiritual suffering of children and their families needs to extend across time and stages of treatment, including bereavement. The clinical course of a terminally ill child can be comprised of periods of chronic strain as well as episodes of acute crisis, which together are a source of unpredictable tension for the families, the ill child, and the child’s health care providers.

There is little empirical research to inform palliative care providers about the psychological and spiritual suffering of children and adolescents facing death. Children’s understanding and processing of death depends on the level of their cognitive development and previous experience. Based on clinical experience, the terminally ill child is reported to grieve loss of function and future and to worry about being forgotten, experiencing pain, and leaving family
members behind in sorrow. Attention has been paid to determining the steps by which children achieve sophisticated understanding of concepts related to death and dying, less investigation has focused on practical issues related to alleviating the psychological and spiritual suffering of terminally ill children. An important role of mental health professionals is to assess dying children for symptoms of depression and anxiety, although such assessment is rarely done.

Families make many practical adjustments in terms of time, money, and location in order to accommodate treatment of the terminally ill child. During end-of-life care, parents can find themselves without the time or emotional resources to care adequately for their healthy children and attend to other personal and professional responsibilities and manage the suffering of their sick child. Siblings report feeling confused, uninformed and worried about their dying sibling’s pain and suffering as well as having worries about other family members and even peers. Parents and siblings show signs of grief while awaiting a child’s imminent death. Psychological suffering is further aggravated when the family’s social networks are disrupted during a child’s end-of-life care when a family or some of its members relocate in order for the seriously ill child to receive specialized care. Future research needs to address the stability of social support for the patient and family from diagnosis through bereavement and the mechanisms by which social support relieves suffering in order to best develop and refine relational (supportive) interventions.

In summary, while research on the identification and amelioration of physical suffering needs improvement, research on the psychological and spiritual suffering associated with a child’s end-of-life is markedly insufficient. Little prospective research has been conducted to examine the longitudinal impact of disease, treatment, and impending death on the psychological and spiritual well-being of dying children and their families. Little more than clinical anecdotes are available in the literature to guide the practice and development of psychological and spiritual interventions. The development of such interventions needs to keep pace with the rapid advances in medical treatments that can foster clinical optimism and prognostic variability that makes a child’s outcome uncertain. This uncertainty may contribute to a different profile of anticipatory grief and bereavement experiences. Research on emerging profiles is needed to develop or refine clinical interventions that are in synchrony with the profile.

COMMUNICATION AT THE END OF LIFE

Informative, effective communication between health care providers and the child’s family is critical when addressing end-of-life issues. Communicating the treatment options for and prognosis of terminally ill children is a delicate process. Unfortunately, this communication can be problematic, deficient, and in some instances even damaging. Parents’ perceptions of insufficient and uncaring delivery of information to them by health care professionals have been associated with lingering regret and emotional distress. Providing parents with the information that they desire in order to participate (to the extent that they prefer) in informed decision making about end-of-life issues should be a primary goal for health care providers. Compassionate delivery of devastating news to the parents of a dying child is likely an important step in facilitating adjustment.

Parents can maintain a sense of hope for their child’s survival even after being told that their child’s death is certain. Respecting parents’ hopes while grounding them in the unfortunate reality of a terminal diagnosis is a delicate and important balance. Families who feel that the medical team is giving up may be resistant to en-
gaging in important treatment discussions related to end-of-life care. Involvement of psychologists and/or social workers has been effective in facilitating the communication of such sensitive information and in turn with higher parent satisfaction with end-of-life care.6,39

Certain factors, such as personal discomfort felt by health care professionals or a focus on cure or survival, may contribute to avoiding or delaying important conversations with patients and families about end-of-life care.30,38 Discussions about do-not-resuscitate orders (DNR) have been reported as occurring only hours before the child’s death,14,36 when parents are already taxed with the emotional burden of their child’s suffering.22 Indeed, nearly 50% of pediatric oncologists who participated in a survey of members of the American Society of Clinical Oncology reported that they only initiate discussions about DNR orders after being prompted by the patient’s family.38 In another descriptive study, a major study finding was the existence of a 3-month discrepancy on average between when physicians and parents first realize that there is no realistic chance for the child’s survival.39 Furthermore, only half of the parents studied learned of their child’s terminal status through direct discussion with the patient’s medical care providers. What these combined study findings do not address is the possible existence of differences in parent satisfaction with their child’s care when they initiate end-of-life discussions or when the health care team initiates such discussions. More research is needed to determine whether a certain parent profile exists regarding preferences for timing and content of end-of-life discussions. To the extent that end-of-life care depends on both health care providers and parents reaching the same prognostic conclusions, addressing any communication barriers is imperative.

Communication about prognosis and end-of-life issues becomes further complicated when disclosure to the terminally ill child is considered. Clinicians generally agree that children should be informed about their prognosis and will benefit from open communication about their impending death.4,25,42–45 Such recommendations about disclosure are based primarily on clinical experience and not controlled clinical trials involving seriously ill children or adolescents. Most initial disclosures to the child about prognosis come from the parents.46 Some parents, in an effort to protect their child and preserve hope, as well as to protect themselves from an unfathomable reality, will resist disclosing to a dying child.43,47 In a recent retrospective study, 27% of parents who did not have end-of-life discussions with their terminally ill child reported regret, whereas all parents who did have such discussions denied having regret.46 More research about disclosure (i.e., timing, who discloses, content of disclosure) and patient and family outcomes is needed. Without data to inform appropriate, effective communication procedures, it remains unclear when discussions should be initiated, what type of information should be provided, and how information should be delivered to dying children. Children differ in the amount of diagnostic and prognostic information that they desire. Some children find it helpful to know detailed information about disease and treatment, whereas others find that same level of information distressing.

**DECISION MAKING AT THE END OF LIFE**

A majority of nonaccidental deaths can be anticipated (although their timing can not); end-of-life care for these children and adolescents will likely include decision making about whether, or when to end curative (disease-directed) or life-extending efforts.6,48 In pediatric oncology, for example, end-of-life decisions such as do not resuscitate, withdrawal of life support, terminal care, or enrollment on a Phase I trial are made with an appreciable frequency from hours to more than a year in advance of the child’s death.6,14,49–51 Who is included in the decision making determines whose care preferences are considered. Some settings exclude parents from such discussions up to 93% of the time and nurses at more than half of the time.52 Some ethnic cultures prefer not to disclose prognosis to the child or parent and thereby exclude both from discussions about care options.33,54 Care outcomes from including or excluding patients and parents from decision making have not been directly compared, and thus we do not have data to help identify characteristics of those patients and parents or other family members who prefer to be included or excluded from the decision making.

Parents report that end-of-life decisions are among the most difficult that they face on behalf of their seriously ill child.55 Yet, an acknowledged
gap in the decision making literature is how seriously ill children and their parents make treatment and end-of-life decisions and what factors influence these decisions. The ability of a parent under duress and competency of the terminally ill child or adolescent to participate in decision making are particular concerns. To begin to address the issues of parent ability and child competency, interview questions derived from a particular decision-making framework (the descriptive-decision-theoretic model) have been used in studies involving terminally ill pediatric oncology patients, their parents, and their health care providers. Study findings indicate that certain seriously ill children and adolescents were able to complete a complex decision-making process in which they considered more than one decisional element at a time and were able to integrate the elements into a decision when risk was involved. Some evidence-based practice guidelines for end-of-life decision making are now available for pediatrics and for neonatology, but they have not been formally assessed in clinical care situations. Mechanisms to support the testing of these and other practice-directed guidelines are needed.

Inclusion in decision making may have profound effects on the quality of survivorship of bereaved family members. In studies involving adults (patients and family members) who are not terminally ill, the satisfaction with participation in treatment decision making influenced satisfaction with care and with quality of medical outcomes at the time of and for months after the actual decision making. These data derived from adults may not apply to the parents of dying children but this needs to be determined.

Current care options for terminally ill children and adolescents can include locale of death and type of care service, i.e., hospital, home, hospital with hospice care or home with hospice, or other form of home-based nursing care. Differences in outcomes of these existing options have not been assessed, perhaps in part because of the low use of hospice care (less than 5% of all dying children in America receive such care). Formal assessment of the effectiveness of different care models on care outcomes is needed. However, given that the majority of terminally ill children die in hospitals (estimates range from 50% to more than 80% of all dying children), and that up to 90% of those deaths occur in pediatric intensive care units after a week of hospitalization, hospitals have the opportunity to define excellence in end-of-life care for children and adolescents. Models of end-of-life care that are hospital-based need to be developed, funded, and evaluated, although not to the exclusion of home-based models.

TOWARD BETTER END-OF-LIFE CARE FOR CHILDREN AND ADOLESCENTS

Many life-threatening childhood illnesses are characterized by prognostic ambiguity and irregular illness trajectories. The unpredictable course of such illnesses has direct implications for palliative care, as the appropriate time to end curative efforts is rarely clearly delineated. This uncertainty likely drives much of the delay in initiating palliative services for sick children. Similarly, families often struggle with the decision to begin palliation in fear that such services imply that the search for cure has been abandoned. To accommodate the uncertain course of disease and to preserve the hope for cure while tending to the child’s physical, psychological, and spiritual symptoms, the integration of palliative care and curative treatment has been consistently recommended. Research about the interface and integration of palliative and curative, and palliative and end-of-life care, is very much needed to benefit the seriously ill child and that child’s family.

Ethical concerns exist about including terminally ill children and adolescents and their family members in clinical research. Proposed end-of-life research is carefully scrutinized by review bodies that weigh the potential risks (e.g., subject matter and timing of contact that could create or add to existing psychological distress, burdens of time and effort) with the potential benefits of new knowledge that could advance care of future children and families. Of additional concern is the ability of terminally ill children to give assent to their participation in research. Concerns have resulted in design alterations that tend to include a more frequent reporting schedule to research oversight bodies, or an added follow-up component to allow a direct assessment of the effects of participation on the dying child and family members.

Concern for burden on the child or family is merited but needs to be balanced by consideration for a child or parent's desire to participate as a way possibly to benefit others. Access to the terminally ill child or adolescent is essential to doc-
ument symptom sensations, efficacy of symptom interventions, factors that the child and family considered in treatment decision-making, or the longer term effects of surviving a child’s death. Follow-up contacts immediately to several weeks after the original study participation with parent participants in end-of-life studies indicate that the majority of parents (ranging from 97% to 99%) report the experience to be valuable and deny regrets about participation. In one follow-up study, 28% of participating parents did report being negatively affected by participation, but no detail about the cause of the negative impact was provided in the report. These few studies involved parents of children with cancer and not the terminally ill child, and thus it is not certain that the findings apply to parents whose child died of other causes.

Clinicians have reported a self-perception of being insufficiently prepared to provide end-of-life care to children and to their family members, having relied upon trial-and-error methods to learn such care strategies. Doubts about their abilities to address adequately patient and family suffering has contributed to some health care professionals exiting from their discipline or from involvement with dying children. Similarly, prognostication accuracy of a child’s death remains difficult. Prognostication relies upon sensitive clinical knowing, scientific knowledge about predictors of fatal outcome, and clinical wisdom. This skill could significantly contribute to facilitating a “good death” by providing the dying child, adolescent, family, and care providers the opportunity to begin preparing for the child’s death. Preparation will mean different behaviors, thoughts, and plans for each individual involved.

Accurate prognostication may be further complicated by an implicit health care practice belief that with enough effort, research, and expertise, the lives of very ill children can be saved—whether that means that the illness is cured, the injuries repaired, or the threat to life is controlled. But children are dying. The proportion of children living with chronic, irreversible disease processes continues to rise, with many of the children and adolescents succumbing to their disease. Certainly more research and knowledge can save lives, but more knowledge about dying can make possible the so-called good death for those children who will die. Health care professionals are quite receptive to opportunities to learn about end of life care. Formal end-of-life care curricula have been developed and are at this time discipline-specific End-of-Life Nursing Education Consortium (ELNEC; EPEC). These curricula have been very well received but an extension of their success to include different and multiple disciplines (as is reflected in the newer IPPC model) would more accurately simulate real clinical care. The educational impact and clinical outcomes of discipline-specific curricula compared to the same from an interdisciplinary curriculum might be quite revealing. The principles made explicit in the developed curricula have seeming applicability to multiple disciplines, and thus it may require minor revisions to offer the existing curricula for end-of-life care to an interdisciplinary group.

A final area of opportunity to facilitate a good death for children and adolescents who will die of disease or trauma is to identify through systematic processes the indicators of quality end-of-life care. These indicators could help to guide health care providers in their care efforts so that they may not have to rely upon trial-and-error learning and could persuade health care settings that excellence in end-of-life care can be defined, made explicit, and thus be achieved.

### CONCLUSION

Significant challenges exist to conducting the critically needed research on dying children and adolescents and their families, to implementing clinical demonstration models of excellence of end-of-life care, and to testing the few available evidence-based practice guidelines related to end-of-life care. These challenges include small numbers of patients with diverse life-ending illnesses, an insufficient number of clinical investigators with experience in conducting end-of-life pediatric research, reluctance of institutional review boards to approve such research because of concerns related to the risk/benefit ratios, the need for targeted funding for testing of guidelines or care models, and a national mechanism (such as a consortium) to conduct pediatric end-of-life research that will yield representative findings related to the characteristics of pediatric deaths and effectiveness of interventions to prevent or diminish the suffering of the dying child and of the bereaved survivors. Outstanding care, both of children facing their end of life and of their families, is worthy of societies’ attention and support.
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