PARENTS’ REFLECTIONS ON THE QUALITY OF DYING AND DEATH OF THEIR CHILDREN IN THE PICU

Diane M. Yorke

A dissertation submitted to the faculty of the University of North Carolina at Chapel Hill in partial fulfillment of the requirement for the degree Doctor of Philosophy in the School of Nursing.

Chapel Hill
2007

Approved by:

Advisor: Diane Kjervik

Reader: Gayle T. Davis

Reader: Barbara Germino

Reader: Susan F. Pierce

Reader: Diane Hudson-Barr
Most children who die do so in the hospital, most often in the PICU. Little is known about how parents view or remember this experience. In this study parents who had a child die in one PICU during 2004 and 2005 (total of 84 children, one set of twins) were asked to share their memories of having a child die in the PICU and to rate the quality of various aspects of their experience. Nineteen parents, one foster parent, and three grandparents of 14 children participated. Parents recalled memories of the experience during an audio-recorded interview. The interviews were loosely structured to have parents address what they remembered about their experiences of maintaining their family roles, establishing relationships with health care providers, sharing and communicating information, pain and symptom control for their child, and the systems of support offered by the health care team. Parents were also asked for their recommendations to improve this experience with the goal of answering the question of what is essential to enabling a good death in the PICU. Parents’ evaluation of the quality of their child’s dying and death in the PICU was determined using a modified version of the Quality of Dying and Death Questionnaire. The aim was to obtain information directly from parents about certain modifiable aspects of end-of-life care for children in...
the PICU. Results suggest that parents of dying children want more direct communication and information about their child’s condition; that they want to remain both present and involved in caring for their child until and after they die; and that they want and need some follow-up contact after their child has died.
To my mother who told me often that I read too much (I did, I probably still do, and if I hadn’t, maybe this project would have been completed sooner but most likely it would have been done with much less enthusiasm); to my father who told me I wanted to have it all (and then saw to it that I could); and to all the parents who have allowed me the privilege to share their experience and thus make this journey.
ACKNOWLEDGEMENTS

In my life I have had the good fortune to meet and know and work with many extraordinary people. This past while, during my adventure through the preparation for and writing of this dissertation, when the absolute frenzy of the experience might have left me isolated and alone, these people made sure I was seldom alone for long. How, at the end of such an adventure, does a person thank everyone that made it possible? I will not mention any of you by name for fear that I will leave one of you off the list. You know who you are. I’m not sure you know how much you mean to me but I wouldn’t be here without you. Much thanks.

I also extend thanks to the School of Nursing and to all the individuals within, especially the members of my committee. I have received so much from everyone here.

As well, my thanks must extend to the UNC Children’s Hospital for being my working home for so long. Without this home, my studies would not have been possible.

Finally, my acknowledgements would be incomplete if I did not say how thankful I am for the care and support and love I receive from my family both near and far.
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PARENTS’ REFLECTIONS ON THE QUALITY OF THE DYING AND DEATH OF THE THEIR CHILDREN IN PEDIATRIC INTENSIVE CARE

Chapter 1

INTRODUCTION

Improving care at the end-of-life continues to be of interest to patients and their families as well as the health care provider community. All of us want our death or the deaths of those we care for to be as near to perfect as they can be. The problem is that there is little literature describing what a near perfect death is. Despite research findings suggesting that patients want both treatments to cure as well as interventions that promote comfort when dying, reports that end-of-life care fails to meet dying patients’ needs and desires continue (Tolle, Tilden, Rosenfeld, & Hickman, 2000; Wolfe, Grier, Klar, Levin, Ellenbogen, Salem-Schatz, et al. 2000). Family members still comment that their dying loved ones are uncomfortable, anxious, and distressed for some time before as well as at the time of their death, and as a result, the health care community struggles to improve the quality of care provided at the end-of-life.

Background

Much of the distress of dying is related to the advances made in healthcare. It is no longer likely that one will die quickly from an infection or injury since there are antibiotics and advanced medical procedures and surgical techniques to treat most ailments. Medical technology has progressed to the point where many deaths are characterized by some time in hospital and frequently some time in intensive care. This
aspect of medicine – being able to provide the most, and what some consider the best medical care and utilizing tremendous, even awe-inspiring technologies – interferes with the ability to define or pinpoint what quality end-of-life care might be. This is especially true in the intensive care setting where the expectation is that every possible treatment will be tried and even more so when the patients being treated are children. There is a medical responsibility to cure disease and alleviate suffering but the technologies developed to accomplish this have blurred our perspective such that suffering and death are frequently seen as medical problems to be solved rather than as experiences in the natural order of things (Kane, Hellsten, & Coldsmith, 2004).

For nurses working in intensive care it is challenging to remember to look beyond the numbers and the various life supporting machines to provide “an embodied nurse-patient relation… looking beyond the technical to "touch" patients” (Sandelowski, 1998). In other words providing patient and/or family centered care in the intensive care unit (ICU) can be confounded by the nature of the setting as well as the patient’s condition. Patient and family centered care principles focus on establishing and maintaining a collaborative relationship among the members of the health care team and the patient and family (Eichner et al., 2003). The central tenant of family centered care in pediatrics is that the family is the constant in a child’s life and as such should be actively involved in communication about and treatment plans for their child. When a patient is dying in the ICU keeping the patient and family at the center of care is critical but may also be complicated by the purpose of intensive medical care. The goal in intensive care is to provide the maximum effort to sustain life and promote healing in patients experiencing life threatening injuries or illnesses. Simply put, intensive care strives to be death
defying. Yet, there is an uncertainty inherent in all intensive care admissions and this uncertainty can interfere with the health care team acknowledging and/or discussing the imminent possibility of death and implementing interventions that focus on providing family centered quality end-of-life care.

The uncertainty of prognosis in childhood conditions, the social expectation for all children to live and be healthy, and the vast array of technological interventions available can instill parents and health care providers with unrealistic hope and an unwillingness to discontinue life-sustaining medical treatment because withdrawal of treatment is seen as ‘giving up’ (Kirschbaum, 1996; Masri, Farrell, Lacroix, Rocker, & Shemie, 2000; Sahler, Frager, Levetown, Cohn, & Lipson, 2000). There is the expectation, especially by parents, that technology can “fix” their child and this expectation can interfere with recognizing when extraordinary medical interventions and measures are no longer of value (Kirschbaum, 1996). Parents may be over optimistic about the possibility of a cure and continue to demand that everything be done (Larson & Tobin, 2000). Also, the extreme anxiety associated with having a child in intensive care can impair parents’ ability to comprehend the information the health care team is presenting to them (Board, 2004; Melnyck, 1994; Melnyck, et al., 1997; Miles & Carter, 1982). There is as well a certain amount of reluctance on the part of physicians in general and ICU clinicians in particular to talk about the possibility of death early in a child’s admission to the ICU. Physicians and nurses may be inexperienced or just uncomfortable in discussing death and dying (Curtis, Patrick, Caldwell, & Collier, 2000; Larson & Tobin, 2000). Regardless, all of these issues can affect the interventions instigated while trying everything to “fix” a critically, terminally injured or ill child. As a result, these
interventions may be maintained up to the moment of death as opposed to providing care that might more readily meet the comfort and information needs associated with quality end-of-life care and providing a good death.

Still, being able to provide a good death in the intensive care unit may be a question of defining a good death as well as recognizing that in some instances providing a good death may not be feasible. “Good death” has been described as “free from avoidable distress and suffering for patients, families, and caregivers; in general accord with patients’ and families’ wishes; and reasonably consistent with clinical, cultural, and ethical standards” (Field and Cassel, 1997, p24). Accepted medical definitions of a good death incorporate pain control, communication among patients, family members, and health care providers, and exploration of the meaning of the dying person’s life (Lynch & Abrahm, 2002). For families of children dying in the intensive care unit a ‘good death’ has been described in terms of the communication and compassion provided to the child and family (Davies & Connaughty, 2002).

But how are these definitions and concepts exemplified in the pediatric intensive care setting and how do the families of children who have died in intensive care remember this agonizing experience? Aiming solely to provide a good death may be inadequate, may even be impossible in certain circumstances. The better goal would be to provide quality end-of-life care, because in the pediatric intensive care unit it is difficult to obtain the optimal setting for the dying patient to experience a good death. The PICU is seldom “a peaceful, private, low-stress environment with ample visitation and little or no extraneous hardware” as Whetstine (2001) describes the optimal setting for a good death. The many and varied technologies and the intensity of care provided in the
intensive care unit do not often permit peace or privacy. The environment of the intensive care unit is by nature high-stress and seldom can intensive care be carried out without life supporting ‘extraneous hardware.’

**Problem**

In countries such as the US, highly developed and widely available medical technologies may lead to prolonging painful, intrusive treatments at the end-of-life that are ultimately futile. Family members of children in pediatric intensive care have listed communication of information about prognosis and treatment in their top five needs (Fisher, 1994; Scott, 1998). Intensive care patients themselves have been described as having “a need to know” (Hupcey & Zimmerman, 2000). However, the urgency with which treatment must be implemented in the intensive care setting may preclude full discussion and/or understanding of what patients and their families ‘need to know.’ The length of stay in intensive care is relatively short and time to death may also be short impeding effective and or timely communication and that leaves end-of-life discussion in the PICU to appear abrupt. Finally, the ability to prognosticate outcomes, especially in children, is often a matter of trying everything until no options remain and there is no gain in improvement. These aspects of the intensive care unit environment can interfere with discussion and follow-up with families about ways to improve the quality of end-of-life care provided in the intensive care unit.

Despite considerable focus on providing and improving the quality of healthcare in general (Aspden, Corrigan, Wolcott, & Erickson, 2004; Kohn, Corrigan, & Donaldson, 2000b; Page, 2004) and the quality of end-of-life care in particular (Field, 1997; Field & Behrman, 2003a; Lunney, Foley, Smith, & Gelband, 2003) little research has focused on
determining what patients and families consider quality end-of-life care to be. The most
interesting finding, though not all that surprising, to result from the available research is
that dying patients and their families hold somewhat different views of what constitutes
quality end-of-life care than the health care team (Shannon, Mitchell, & Cain, 2002).
While the health care team focus has been on the ability to extend the amount of time one
is alive, dying patients and their families have reported more concern with the quality of
living during their final days. The components of quality end-of-life care from the adult
patient’s perspective have been reported as receiving adequate pain and symptom
management, avoiding prolonged dying or inappropriate interventions, maintaining a
sense of control, and strengthening relationships (Singer, Martin, & Kelner, 1999).
Similar expectations for the care of children at the end-of-life have been suggested:
parents have indicated satisfaction with the overall quality of care provided at their
child’s dying; however, these same parents reflect back on the discomfort and
apprehension their child experienced at the time of death as unnecessary and treatable
(Wolfe et al., 2000).

Though increasing attention is being paid to the quality of end-of-life care for
children, most end-of-life research has focused on dying adults and the families of dying
adults. Some of these research findings are easily generalized to dying children. For
example, families of both dying adults and dying children desire good pain control for the
patients and good information sharing for themselves around and at the time of death.
Researchers have not considered that in our society the death of a child is out of the order
of things. Certainly, children are not expected to die before their parents. Parents in the
US today both hold themselves accountable and are regarded as responsible for the health
of their children. As well, parents remain the ultimate decision makers for their children. This awe-inspiring responsibility may also interfere with parents’ ability to withhold or withdraw medical treatment at the end-of-life.

The advances in medicine and technology during the last century have made dying children not only a rarity but also something of a dilemma; “…children who die are problematic because they can only signify failure: failure of the scientific and caring systems which should have kept them alive…” (Avery and Reynolds, 2000, p.8). Childhood death is no longer expected or readily accepted. This is another difference that families of dying children experience compared to that experienced by family members of dying adults (Goldman, 1998; Rando, 1986). In dealing with the death of their child, parents, and other family members, face their own mortality, may have ongoing feelings of blame or guilt, and must come to accept the loss of the expectations they held for themselves to experience with their child as well as their expectations for their child’s future. The death of a child has been found to produce the highest levels of bereavement and the widest range of short and long-term reactions (Sanders, 1980). Most importantly though, as already mentioned, both the family and the health care team do not expect children to die and frequently do not know how to approach this possibility. Even if or when a child’s death is anticipated, as in the case of serious chronic illnesses such as cancer or cystic fibrosis, social taboos have constrained discussion of what might be expected and what might be desired as death approaches. There might even be an element of denial when parents and the healthcare team face a child’s death; if we don’t talk about it we can maintain a ‘mutual pretense’ that death is not expected and continue to act as though it will not occur or that it can be avoided (Bluebond-Langner, 1978;
Glaser & Strauss, 1964). This pretense, that death is not expected or can be avoided, permits the family and the healthcare team to continue to implement medical treatments or interventions that may pass the point of benefit to the dying child. Additionally, it may impede providing the dying child and his or her family of quality end-of-life care that includes the elements of pain management, family presence, communication and information. As already mentioned, in the intensive care setting there is often an urgency with which treatments need to be implemented. This urgency is felt to supersede and may even interfere with recognition of the need for and the implementation of some or all of the elements of family centered and quality end-of-life care. More importantly, it seems that there is seldom discussion of what everyone desires, expects, and can look forward to. All of this makes end-of-life care for children in the ICU setting difficult and often unsettling.

Traditionally, care in the ICU has been viewed as curative and life-prolonging, aimed at making the patient better. However, 20% of all patients admitted to adult ICUs (Taylor-Thompson, et al. 2004) and 5% of patients admitted to pediatric ICUs die there (Levetown, Pollack, Cuerdon, Ruttimann, and Glover, 1994). Lacking accurate prognostication tools, physicians in intensive care have been urged to contemplate the likelihood of their patient dying in the next day, week, month, or longer in order to focus consideration on the possible need for end-of-life care. The advances in nursing, medicine and health care technology have blurred the distinction between intensive care and end-of-life care and have led to the suggestion that palliative care be integrated across the time a patient and his or her family is in the ICU (Nelson & Danis, 2001). Instigating palliative care at the start of an intensive care unit admission is thought to be
able to make the implementation of end-of-life care when it is indicated easier and less sudden (Curtis and Rubenfield, 2001).

A brief definition of palliative care is in order. Palliative care has been considered “… the active total care of patients whose disease is not responsive to curative treatment” (World Health Organization, 1990, p.11). The definition for palliative care also considers “care that seeks to prevent, relieve, reduce, or soothe the symptoms produced by serious medical conditions or their treatment and to maintain patients’ quality of life” (Field & Behrman, 2003, p. 2). More recently, researchers and clinicians have proposed that palliative care is a component of curative and life-prolonging treatment (Meier, 2005). In the ICU setting, palliative care is argued to be an integral aspect of intensive care that begins on admission and continues until discharge or death (Mularski, Bascom, & Osbourne, 2001). For children palliative care involves “the active total care of the child’s body, mind and spirit, and also involves giving support to the family. It begins with diagnosis…” and continues across the spectrum of the illness. Most importantly, palliative care for children includes and involves the family (World Health Organization, 1998, p.8). Palliative care begins before but is also a component of end-of-life care. For children who die suddenly and for those requiring intensive care at the end of their lives, an aspect of palliative care is providing bereavement and grief support that will aid survivors in adjusting to their abrupt loss. One means of providing this support is in providing survivors the opportunity to reflect on their experience of loss. Research indicates that what families remember about their child’s death can influence their health and coping for some time (Picard, 2002; Rando, 1986). Being able to talk about their child and their experience of his or her dying reaffirms for parents the social standing of
their child, their child’s importance to them as parents and the child’s contribution to the world (Klass, 1997; Schatz, B. D., 1986; Schatz, W. H., 1986). Parents who have had a child die report that it takes 3-4 years for them to reestablish an emotional equilibrium (Klass, 1997) and that this often is dependent on being able to talk about the connections they had and still feel with their late child.

Having the opportunity to discuss a child’s death can decrease the feelings of social isolation and loneliness often reported by parents who have had a child die. This is consistent with research findings that people experiencing traumatic losses report positive effects from participating in research where they are the focus of interest, concern, and caring attention (Cook & Bosley, 1995; Dyregrov & Dyregrov, 1999; Dyregrov, Dyregrov, & Raundalen, 2000; Parkes, 1995) and have found participation therapeutic (Dyregrov, Dyregrov, & Raundalen, 2000; Hawton et al., 1998; Riches & Dawson, 1996). But the opportunities for discussion are reported to be rare for most bereaved parents and the situation has been likened to not acknowledging that there is an elephant in the room: everyone knows the elephant is there but no one will talk about it. Similarly, many parents of children who have died find that quite quickly after their child’s death their friends and loved ones no longer want to mention or talk about the child who has died. In turn, this lack of discussion may prolong the grief of parents in that they are discouraged, or at least not encouraged, to remember, reflect on, and have others recognize the importance of their child’s life. "Summarizing, when someone is dying or has died there are few chances to talk about it whether there is little opportunity (no one to talk with) or lack of time (as in the intensive care setting)."

The literature to date lacks information about how parents reflect on their child’s
death in the intensive care setting. In addition, there has been no investigation of parents’ suggestions for improving care for the families and pediatric patients who die in the Pediatric Intensive Care Unit (PICU). There is a push to implement palliative care principles for all patients (Miller & Fins, 1996; Roman, 2001) including patients in intensive care setting (Nelson & Danis, 2001; Randall & Rubenfeld, 2001) but at present there are few guidelines for implementing these principles in the ICU (Truog et al., 2001). Palliative care exists on a continuum with curative measures and is suggested as the means to providing good end-of-life care. This continuum is depicted in the model in Figure 1.

**Continuum of care**

![Continuum of Care Model (EPEC, 1999)](image)

**Figure 1.** Continuum of Care Model (EPEC, 1999)

At an initial diagnosis, the focus is on providing curative care – finding a means to alleviate the disease. If the patient’s disease or condition worsens or fails to respond to treatment, the focus reverses so that the concentration is on palliating symptoms while maintaining appropriate treatments, while not escalating medical or technological
interventions. On the medical intervention-palliative care continuum, as the likelihood of death escalates treatment shifts from prolonging life to alleviating pain and improving quality of life. Yet in the intensive care unit, this change of focus in medical care is often not gradual and has not been discussed or implemented prior to the discussions with families about the need to limit or withdraw medical interventions. This change in care focus can be confusing to families and can even give the appearance of being abandoned as complex and technical interventions cease. Parents see fewer members of the health care team intervening with their child and may not recognize or even be aware of the increased presence at their child’s bedside of a select few members of the health team staff.

Discovering what aspects of palliative care or end-of-life care parents value when their child has died in the PICU is necessary if the end-of-life care provided to the children dying there as well as the care of their parents and families is to be improved. Perspectives of parents of children who have died in intensive care will offer insight regarding how to implement effective palliative care measures in the pediatric intensive care unit.

Purpose and Specific Aims

The purpose of this study is to explore with parents and families who have had a child die in the PICU their thoughts and memories of this experience in order to determine how the care they received might be improved. The goal ultimately is to improve the quality of the end-of-life experience for other children and their families. The goal is not to elicit from parents a list of needs during the time that their child was in the hospital – this has been done very adequately (Fisher, 1994; Henneman & Cardin, 1992; Kutner, Steiner,
Corbett, Jahnigen, & Barton, 1999; Meyer, E.C., Burns, J.P., Griffith, J.L., & Truog, R.D., 2002b; Meyers, 2000; Price, Forrester, Murphy, & Monaghan, 1991; Scott, 1998). Rather, this research aims to give parents the opportunity to reflect back on the experience of having had a child die in the pediatric intensive care setting and describe what would have or might have made this experience less disturbing to them and their dying child. This is important to know given the interest and investment in improving the quality of care of children at the end-of-life.

Elucidating parents’ perceptions of their child’s end-of-life experience may provide direction for improving the end-of-life care for children (Kirschbaum, 1996) as well as improving the families’ experience and memories of their child’s dying (Lynn & Moore, 1997). Knowledge of the memories of and the suggestions for improvement from parents of children who have died in the ICU will enable more appropriate implementation of palliative care practices in this challenging setting. Ultimately, the most effective way to improve the quality of end-of-life care for children dying in the intensive care setting is by exploring with parents who have had a child die in the PICU their experience, their memories, and their ideas of what might have or could have been improved.

**Research Questions**

Thus, the research questions that guide this study are the following:

1) What experiences do parents who have had a child die in the PICU recall about:

   a. maintenance of family roles in the PICU?
   b. establishing relationships with care providers?
   c. information exchange among parents and health care providers?
   d. pain and symptom control for their child?
e. systems of support offered by the health care team?

2) What recommendations do parents who have had a child die in the PICU make to improve this experience?

3) What do parents consider essential to enabling a good death for children who die in the PICU?

4) How do parents of children who have died in the PICU evaluate the quality of dying and death in the PICU?
   a. What aspects of the dying and death in the PICU do parents of a dying child identify as high quality?
   b. What aspects of the death and dying experience in the PICU do parents of a dying child identify as low quality?
Chapter 2

LITERATURE REVIEW

Discussing end-of-life care and means to improve it requires some understanding of the principles of quality and how quality of health care is investigated in general. Often used are consumer definitions of the domains of care. Similar conceptual models for evaluating quality at the end-of-life have been suggested. As well, examining what constitutes ‘good’ in terms of dying is integral to deciding if improvement can be made in providing end-of-life care. The focus of this literature review is to examine the above concepts in order to provide a background to the investigation of what parents remember about the quality of their child’s dying and death in the pediatric intensive care unit as it pertains to maintenance of family roles, establishing relationships with health care providers, receiving and exchanging information, the pain and symptom control experienced by their child, and the systems of support offered by the health care team.

Quality

While quality is recognized as a difficult to define concept, it has been associated with the attributes of excellence, the ideal, meeting requirements, satisfying need, and/or providing customer value (Attree, 1993; Shannon, Mitchell, & Cain, 2002a). In a brief review Hoyer and Hoyer (2001) outline several of the many definitions of quality proposed by quality experts: Philip Crosby suggests that quality indicates a relative worth of things; Deming states that quality can be defined in terms of either the producer of a good or service or by the specifications of the consumer of the good or service; for
Armand Feigenbaum quality is determined by the customer’s actual experience with a product or service and is evaluated against his or her expectations and requirements; Ishikawa equates quality to consumer satisfaction in the face of changing customer needs and expectations; Joseph M. Juran writes that quality has many meanings but is most often defined as the features of a good or service that satisfy the needs of customers for the product and the degree to which the product, good, or service is free from deficiencies; Pirsig, on the other hand, has suggested that it is not possible to define quality but that it is almost always recognizable by excellence, worth, or goodness; finally, Walter Shewhart states that measurement of quality requires recognition of both the objective (properties of the product, independent of what the customer wants) and subjective (what the customer wants) aspects of an experience with a product, good, or service. This last definition helps shape the definition of health care quality.

**Health Care Quality**

Health care quality has been defined as "the degree to which health care services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge" (Lohr, 1990, p707) and as the worth or excellence of various attributes of medical care (Davies & Ware, 1988). These broad conceptual definitions of health care quality suggest that quality in health care reflects the interplay among the evaluation of the setting of care, the manner in which care was decided upon and delivered, and the results obtained from the care. In the case of parents of children who have died in a PICU the memories of this experience shape their evaluation of the quality of dying and death experienced by their child.
It has also been suggested that quality health care means doing the right thing, at the right time, in the right way, for the right person - and having the best possible results (Agency for Healthcare Research and Quality, 2004). For individual patients health care quality has been defined as the ability of individuals to access the health care structures and processes of care that they need and whether the care they receive there is effective (Campbell, Roland, & Buetow, 2000). Notably, health care quality is “something towards which we constantly strive and which we may never achieve” (Redfern & Norman, 1990, p.1261). For those whose end-of-life care is delivered in the intensive care setting there should be ongoing discussion of how to decide what is the right amount of care and when to limit, withdraw, or change the focus of care. In other words, what is the right thing, the right time, the right way, and the best result a patient who is dying in the ICU setting can expect?

Assessing quality in healthcare involves the same procedures as assessing quality in any other product or service, that is specifying criteria, norms, and standards that indicate whether ‘good’ or ‘bad’ care has been provided or received (Donnabedian, 1980). This quality assessment requires consideration of multiple variations on the technical and the subjective or interpersonal experience of health care encounters (Brook & Lohr, 1985) as well as on the dimensions of accessibility and effectiveness of health care received (Campbell, Roland, Buetow, 2000). Assessing the quality of health care for children is complicated further by their development (children experience many rapid developmental changes that affects their understanding of need for differing levels of care) , dependency (access to health care for children is dependent on their caregivers), different epidemiology (few children have chronic conditions and relatively few children
die each year as compared to adults) and demographics (children are more likely to have limited access to health care because of poverty) (Beal et al., 2004). In end-of-life care, quality assessment can be addressed by discovering if the patient received all the care warranted. However, it remains difficult to assess whether a deceased patient feels that all warranted care was delivered. It is easier to discover if the surviving family members perceive that all the care warranted was delivered as well as how these surviving family members remember this experience.

The subjective dimension that influences assessment of the quality of care received is the personal interpretation of the experience made by the patient or the patient’s family. The substance and sensation of the health care episode is assessed mainly by the character of human relationships the patient and the patient’s family has with the health care providers caring for them (Gerteis, Edgman-Levitan, Daley, & Debanco, 1993) and that the assessment of “high quality health care … is influenced predominantly by social values” (Redfern, & Norman, 1990, p. 1261) as well as the individual’s needs and expectations. Thus, assessment and judgment of the quality of care depends on the context in which it (health care) is considered as well as on the person making the assessment. In essence, the extent to which different domains of care are perceived as being received or delivered determines the quality of care.

A systems approach identifies aspects of health care quality under three domains, the structure, process, and outcomes of care (Donnabedian, 1980). The organizational system or factors of care such as the physical layout and characteristics of staff constitute structure of the health care environment. The interactions that users of the system have with the system are the processes of care. The consequences of these interactions are the
outcomes of care. However, despite acceptance of this systems approach to evaluating health care quality, it does little to include the individual user or provider in evaluating health care quality. To this end it has been suggested that the concept of quality of care is more meaningful when applied to individual patients addressing access (whether an individual can get the care he or she needs when they want it) and effectiveness (was the care received beneficial in terms of both clinical effectiveness and inter-personal relationships) (Campbell et al., 2000). With regard to end-of-life care in the intensive care unit, quality of care addresses whether the patient or family got the care they wanted in terms of their need for information, communication and support.

**Domains of care**

Consumers’ opinions of the domains of health care quality are described in *Envisioning the National Health Care Quality Report* (Hurtado, Swift, & Corrigan, 2001a). These domains center on related categories: accessing care and staying well; getting treatment when sick; living with illness; adapting to health changes over the lifespan; and, coping with the end-of-life (Hurtado et al., 2001a). This last domain considers the healthcare adaptations anticipated and worked towards at the end-of-life. For children it has been suggested that quality domains also consider safety, effectiveness, patient and family centeredness, and timeliness (Beal et al., 2004). Regardless of which domains are considered when determining the quality of a health care encounter, the focus of care and the judgment of the quality of care by consumers lies along a continuum and changes over time and largely depend on the specific health care needs of the consumer at any given time. For example, the focus parents place on
judging quality of health care depends on the location where care is being delivered be it
a primary health clinic, a general pediatric ward, or the intensive care setting.
Parents of children visiting primary care clinics were asked to rate the importance of
previously determined attributes of health care quality (Oermann, Lambert, & Templin,
2000). The participants in this exploratory study were recruited by convenience sampling
from waiting rooms of clinics in the Midwest. They were asked to complete the Quality
Health Care Questionnaire (QHCQ), a Likert scale tool designed by the study’s
researchers to rate the importance of 27 attributes of health care and nursing care quality.
The researchers found that these parents defined high quality health care as having access
to care and to competent and skilled providers; receiving the proper treatments for their
children, having effective communication with health care providers, and having health
care providers demonstrate care and concern. While communication is listed as
important, it was not the most important aspect of care for parents of children in this
primary care setting. Of note is that none of the respondents’ children had been
hospitalized during the six months before the study limiting the extent of generalizability,
application, or consideration of this definition of high quality health care to the hospital
setting.

To investigate the hospital characteristics associated with high quality pediatric
care the results of surveys from over 6000 parents of children who were discharged from
38 hospitals using the Picker Institute’s Pediatric Inpatient Survey were analyzed (Co,
Ferris, Marino, Homer, & Perrin, 2003). This survey measures the quality of inpatient
care along seven dimensions including information to parent and information to child.
The researchers found that while parents in the study rated their child’s care as ‘very
good’ they still reported problems with the dimensions of care related to information
sharing and care coordination. Parents rated the quality of the direct care their child
received as good but perceived shortcomings in the interpersonal aspects of care. For
these parents evaluation of high quality care in hospital for their children was dependent
largely on the level of communication they experienced with the healthcare team about
their child’s condition and treatment. In the hospital setting communication with or from
the health care team is viewed as very important and plays a large role in parents’
evaluation of the quality of care provided to their hospitalized children.

Parents of children who died in one intensive care unit were asked to complete a
survey that rated their perceptions of the quality of communication, pain control, support
provided, and their involvement in decision making while their child was in the ICU
(Meyer, Burns, Griffith, and Truog, 2002). The researchers suggest that parents’
perspective of quality care at the end-of-life in the pediatric intensive care includes being
informed and having opportunity to discuss treatment plans and options, receiving
prognostic information regarding their child’s potential quality of life, level of pain, and
likelihood of survival, and most importantly having their child’s pain controlled. For
parents with children in the intensive care unit, quality of care for their children is judged
primarily by two aspects of care: adequacy of symptom control and sharing of
information. The more severe the condition and, subsequently, the more complex the
medical treatment, the more parents want information and pain control for their children.
Uncertainty in the face of their child’s hospitalization can affect parents’ perception of
the seriousness of their child’s condition, their judgment of the quality of care received,
and their level of satisfaction with care (Mishel, 1983) so it is not surprising that parents
in the uncertain environment of the ICU evaluated quality of care on aspects of how well their uncertainty was relieved, that is how well they judged the communication of information from the ICU health care team.

Studies that ask patients to rate their satisfaction with care received as a means to evaluate or judge the quality of care assume that if a patient is satisfied, their expectations for care have been met and the care they received must have been good or at least of acceptable quality. Individuals are assumed to know quality care when they receive it. But this is not always a valid assumption since individual expectations of quality vary. Asking only for information of if or how much a patient was satisfied with a health care experience, limits the amount and type of information obtained. One study of families of patients in intensive care found that families generally were highly satisfied with the care their critically ill family member received in the intensive care unit. However, their satisfaction was greatly influenced by their perception of the quality and quantity of information and communication received from the health care team (Heyland et al., 2002). In one recent study of patient satisfaction patients rated their satisfaction with care very highly despite professional judgment that the level of technical care delivered to these patients was substandard (Chang, et al., 2006). Because patient reports are subjective and influenced by patient needs, biases, and recollections it is more valuable to ask about the experience for the patient both as the patient perceived it and to its relevance for the patient (Drain & Clark, 2004). The best assessment of quality of health care is the patients’ perception of how responsive the health care provider or system was in meeting his interpersonal needs, not just his physical needs. In the case of a deceased
patient, the best assessment of the quality of health care is how well these needs were met in the opinion of his or her survivors.

Assessment of the quality of care is also influenced by perspective. Different persons have different perspectives of and rate quality of care differently depending on their viewpoint, knowledge base, and previous experience. Researchers (Shannon et al., 2002a) reviewed the satisfaction and quality of care ratings from 489 patients who had been in one of 25 critical care units. They also obtained ratings of patient satisfaction and quality of care from 518 nurses and 515 physicians working in the same units. Data was aggregated to the critical care unit and not to individual patients or clinicians. They found that physicians have higher opinions of patient satisfaction and unit quality than nurses or patients. Nurses and patients gave similar ratings to patient satisfaction but nurses rated the quality of care in the unit lower than patients did suggesting that the nurses were aware of aspects of care that could be improved. The study did not explore why the nurses rated quality of care lower, but it may be that these nurses were judging the technical aspects of the care provided as was done in the above mentioned study by Chang et al (2006).

*Quality End-of-Life Care*

The assessment of the quality of end-of-life care regardless of setting has focused on aspects of the environment, the perceived amount of comfort provided, and the level of communication between patients and care providers. The Institute of Medicine Report, *Approaching Death* (1997) identifies six elements for quality end-of-life care: overall quality of life, physical well-being, psychosocial well-being, spiritual well-being, patient perception of care, and family well-being and perceptions of care. More recently the
domains of care identified for quality end-of-life care have been restated: patient and family centered decision making; communication within the health care team and with patients and families, continuity of care, emotional and practical support for patients and families, symptom management and comfort care, spiritual support, and emotional and organizational support for clinicians (Clarke et al., 2003). Quality end-of-life care in the intensive care unit also involves sharing decision making among members of the healthcare team and the patient or patient’s surrogates and assuring a pain free death (Thompson et al., 2004).

Patients, too, have described additional elements of quality end-of-life care. Singer and Bowman, (1999) discovered that patients identify quality end-of-life care as providing pain and symptom control, avoiding inappropriate prolongation of dying, permitting patients a sense of control, relieving the burden of loved ones, and allowing the patient time and circumstance to strengthen relationships with loved ones. Steinhauser et al. (2000) found that patients and their families consider the physical elements of care only one component in outlining what is important at the end-of-life. While the health care team focuses on physical treatment, patients also consider social, emotional, and experiential aspects in determining quality end-of-life care.

In another study, transcripts from focus group meetings with bereaved family members were analyzed to discover what was considered quality end-of-life care. In this research, Teno, Casey, Welch, and Edgman-Levitan (2001) identified five themes that bereaved family members associated with quality end-of-life care. All of these themes reflect the principles of family/patient centered care: meeting needs for physical comfort; being involved and in control of care decisions; being assured that the best care is being
given; being prepared for and educated about what to expect as dying became imminent; and, being provided emotional support both during and after the time of death.

Similar principles of family centered care are reflected in the priorities parents of children dying in the intensive care unit identify for quality end-of-life care: honest and complete information; accessibility to staff; coordination of communication and care; emotional support of patients and parents by staff; maintenance of family roles especially of the parent-child relationship; and, having faith (Meyer, Ritholz, Burns, and Truog, 2006).

**Good versus Bad Death**

Quality end-of-life care is assumed able to ensure patients are provided with a good death. But what is a good death? The Institute of Medicine describes a good death as being free from avoidable distress and suffering for the patient, family and caregivers, while also considering the wishes of the patient and family, and attending to cultural, ethical, and clinical standards (Field, 1997). Pain must be relieved and comfort ensured for both the patient and family for survivors to remember the death as ‘good.’ It is also suggested that a good death is “peaceful and dignified” (Cardoza, 2005), without unnecessary suffering or prolongation of dying (Meyer 2002). A most recent definition is that a “good death is a multidimensional, ceaseless individual experience based on personal and sociocultural domains of life that incorporate the person’s past, present, and future” (Hattori, McCubbin, and Ishida, 2006). These are formal definitions suggested by researchers and organizations within the health care community. Further explication of what constitutes a good death comes from research of patients’ perspectives.
In one study, Steinhauser et al. (2000) interviewed patients, recently bereaved family members, and health care workers. The authors asked these subjects to identify attributes associated with a good death. Subjects described six common components: appropriate pain and symptom management; communication and clear decision making; preparation for death, what to expect and time for planning; completion or finding meaningfulness at the end-of-life; contributing to others; and affirmation of the whole person, his or her uniqueness. In addition, the majority of survey participants agreed that both pain control and having time to prepare for the end-of-life are critical elements of a good death. The findings suggest that comfort, communication, preparation, and completion are valued at the end-of-life by patients and their families. Interestingly, in this study, healthcare providers overwhelmingly underrated the importance to patients of remaining aware, of not being a burden to family members or society, and being able to help others as components of a good death. Steinhauser’s work illustrates how dying and death are multifaceted experiences for all individuals involved.

Pierson, Curtis, and Patrick (2002) interviewed AIDS patients with the goal of describing a good death from the perspective of patients imminently facing death. These researchers found that the components of a good death for these patients are inter-related and vary in importance and definition from patient to patient. An important further finding is the emphasis these ill patients placed on the practical details of the dying process. Having people present, selecting their place of dying, resolving issues and being able to say good-bye, participating in treatment decisions, having the opportunity to visit with clergy, controlling the death scene, being able to opt out of continued suffering, having access to appropriate treatment from healthcare workers they have formed a
relationship with, and, finally, having come to some mental acceptance that they are going to die were all factors that contribute to a good death.

In a similar study out of the Netherlands, Goldsteen, et al. (in press), interviewed patients, their families, and their caregivers, about their experiences with the patients’ upcoming death. Patients in this study were adults (39-83 years) not expected to live beyond three months. The researchers found that the dying patients formed expectations about death and dying that reflect certain current perspectives: awareness and acceptance or resistance; having open communication with family and caretakers; living life until the end; taking care of final responsibilities; and, dealing with emotions. Dying patients are actively involved in creating meaning out of their individual experiences. These authors suggest that it is the context of an individual’s life that is central to determining whether death is or is not good. For parents, too, the ability to construct meaning out of their child’s life and death contributes to shaping the memory of this death as either good or bad (Zeitlin and Harlow, 2001).

In another study, family members were asked for their suggestions on providing a peaceful death experience within the hospital setting (Pierce, 1999). Families suggested that the negative aspects of having a loved one die in the hospital could be lessened by improving and encouraging interaction between the patient, family, and health care team. The families in this study suggested that the hospital environment could be altered to make these interactions more likely and satisfying. As mentioned earlier the intensive care setting can interfere with providing a peaceful death especially if the imminence of dying has not been accepted and aggressive treatment continues.
The nursing perspective of ‘a good death’ is centered on the ability to provide comfort to all involved. The standards of nursing care outlined by Ruland and Moore (1998) exemplify this. These standards form the basis of their theory of the peaceful end-of-life: that patients should not be in pain; that their comfort should be assured; that dying patients experience respect and dignity; that a sense of peace is pursued; and, that physical closeness of persons that matter to the dying patient is ensured. As well, these suggestions reiterate what has been called the common professional definition of a good death: symptoms are controlled; death has been acknowledged and accepted; and, plans have been made so that all involved are satisfied (Hopkinson and Hallet, 2002).

Hopkinson and Hallet (2002) reviewed seven studies that examined what nurses consider an ideal death. In all seven studies, the nurses listed symptom control and patient comfort as a main component of an ideal death.

What constitutes a good death has also been investigated from the perspective of intensive care nurses. That nurses want to be able to provide patients with appropriate end-of-life care is not extraordinary. However, trying to provide what they consider appropriate in the midst of the intensive care setting can be unsettling. Beckstrand, Callister, and Kirchhoff (2006) asked nurses working in critical care settings for their suggestions to improve end-of-life care in the ICU. The participating ICU nurses discussed problems such as staffing numbers, lack of honest communication between physicians and patients/families, and identified the possibility that physicians in intensive care see death as a defeat as impediments to providing a good death. However, this same group of nurses were also able to suggest five areas that facilitate providing a good death: making environmental changes to promote dying with dignity; being present and
providing for family presence; controlling patient pain and discomfort; discovering and following patients’ and their families’ wishes for end-of-life care; ending aggressive treatments earlier or not starting them at all; and, effectively communicating as a healthcare team.

Few studies though have investigated the definition of a good death from the parents’ perspective, fewer still in the pediatric intensive care setting. Only two reports were found that asked parents’ their opinions of end-of-life care in the pediatric intensive care unit with both reports coming from one large three-site study. In the first report, Meyer, Burns, Griffith, and Truog, (2002) administered a self-administered questionnaire to 96 parents of pediatric patients (newborn to 18 years of age) who died in one of three Boston pediatric intensive care units after withdrawal of life sustaining treatments. Fifty-six different parents responded (58%). These parents placed the highest priority on their child’s quality of life and expected quality of life; the likelihood for improvement in their child’s condition, and, management of their child’s pain and comfort in making their decisions.

In the second report, Meyer, Ritholz, Burns, and Truog (2006) asked the same 56 parents from the above mentioned study open-ended questions aimed to identify and describe from their perspective as parents priorities and recommendations for end-of-life care and communication. The authors report that parents of children dying in the pediatric intensive care unit identify six priorities for pediatric end-of-life care: honest and complete information; available staff; coordination of care and communication; acceptance of and emotional support and expression from staff; maintenance of family roles; and, recognition of the importance of faith to patients and families. Both of these
studies provide some indication of what parents consider a good death for a child and the aspects of care in the PICU they identify in need of improvement.

**Framework for the study**

This discussion of what is a good death illustrates the necessity for considering a multitude of perspectives and conditions. Fortunately, an existing framework brings all of these varying but related conditions for understanding and evaluating a good death together. Emanuel and Emanuel, (1998) proposed a framework (see Figure 2) for a good death that includes aspects of care across the multiple dimensions of a patient’s condition. These include the patient and their family’s financial situations, care and caregiver needs, social relationships, plans and thoughts of the future, and spiritual and existential beliefs. For a patient to have a good death interventions must be directed to meeting their needs for family, relationships, information, symptom control, and social support.

For this study the Emanuel and Emanuel (1998) model has been adapted to demonstrate how the fixed characteristics of the patient and family shape potentially modifiable dimensions of the experience (see Figure 2). Both the fixed and modifiable characteristics identified in this model should influence and guide the health care system interventions that are provided for parents during their child’s dying in the PICU. Fixed characteristics of the patient include age, diagnosis and disease prognosis. For the parent the fixed characteristics are age, level of education, and ethnicity. Potentially modifiable characteristics for the parents or survivors are the child’s experience of symptoms and their own experience of psychological distress, provisions made to maintain an intact family system and allow family participation in care, and parents’ ability to frame or reframe the hopes and expectations they had for their child and make some meaning of
Figure 2.
Framework for a Good Death
(Adapted from Emanuel and Emanuel, 1998)
their child’s life. The experience of having a child die in the PICU is shaped by how well the health care system interacts with and responds to these modifiable characteristics of the patient and family.

It is the memory of the experience that survivors hold after the death of a loved one that frames their evaluation of the death in terms of goodness or badness: “How people die remains in the memories of those who live on” (Sanders, 1989, p.624). This study will examine parents’ memories of how their child died in the pediatric intensive care unit and compare these memories with their ratings of the quality of dying and death of their child using a modified version of the Quality of Dying and Death Questionnaire.
Chapter 3

METHOD

Purpose and Problem Statement

The purpose of this study was to obtain parents’ perspectives on having had a child die in the pediatric intensive care unit (PICU). The aim was to use this information to make recommendations to restructure and improve the quality of end-of-life care for children dying in this setting. Little is known about what parents consider a good death for their critically ill and dying children. Even less is known about what reflections parents have regarding this experience. To date parental perspectives and suggestions for improvement have not been utilized in restructuring, changing, and improving the experience for parents of having a child die in the PICU. Research suggests families are generally quite satisfied with the end-of-life care received by their loved one in the ICU setting (Heyland, Rocker, O'Callaghan, Dodek, & Cook, 2003) but only one study has sought to identify parents’ priorities and recommendations for improving the quality of end-of-life care delivered in the PICU (Meyer, Ritholz, Burns, and Truog, 2006). Work is in progress to adapt the Quality of Dying and Death instrument for the pediatric intensive care population (The PICU Study – RO1 NR09298-01A1 – Truog (Principal Investigator), Sellers (Project Director).

Setting

This PICU has 16 patient beds and an all RN nursing staff. The nurse to patient ratio is usually in the range of 1:2 to 1:1 and sometimes even 2:1, depending on the
severity/acuity of patients’ conditions. The ages of patients are from newborn to late adolescence (~20 years). These pediatric patients present with a wide variety of critical, life-threatening, and life-limiting conditions such as serious congenital heart disease, end stage organ failure, trauma, cancer, and rare metabolic diseases. During the years 2004 and 2005, this PICU experienced 40 and 44 (one set of twins) deaths respectively.

Subjects and recruitment

The target population for this study was the parents or guardians of the children having died in the PICU from January 2004 through December 2005. This would have been at least one year since their child’s death. Letters of invitation to the study were mailed to the last known address of 80 parents. Three families had no last known address or phone number so no further contact was attempted.

This researcher remains a practicing nurse clinician in the Pediatric Intensive Care Unit that is the setting for this study. This may be regarded by some as a potential threat to the objectivity of the findings or even to the study itself. However, in human science research it is the involvement of the researcher, his or her commitment to the investigation, that permits both interpretation and integration of observations and data (Alberty, 1990). Without close involvement, the qualitative researcher may find him or herself simply going through the process of documenting observations rather than interpreting them. Being involved within the setting of the phenomenon and committed to it brings perspective otherwise unattainable. This researcher’s awareness of this setting and experience provides insight for interpreting and rendering the experience as described by parents of having a child die in the pediatric intensive care unit.
There is also the possibility that my close involvement in the PICU where parents have had a child die may have influenced their comments. Parents may not have felt open to make suggestions for improving the end-of-life care in the PICU where this researcher continues to work. However, throughout data collection the parents in this study readily recognized, admitted, and/or verbalized that the death of a child is one of the worst things that could happen to any parent and they were open to discussing ways that might make the situation better for others. I had planned not to interview any parents of patients I had direct patient care responsibilities for at the time of their death\(^1\). Objectivity was also increased by having the audio recordings of the interviews professionally transcribed. Corrections were made to the transcriptions and field notes added during re-listening to the tapes.

The rigor of qualitative studies is determined by the trustworthiness of the data, the coherence of the presentation, and the meaning that flows from reflection and interpretation. To establish trustworthiness the researcher documents, usually in the form of a journal, his or her assumptions, relationship with participants, means and methods of obtaining and recording data. “Trustworthiness becomes a matter of persuasion whereby the scientist is viewed as having made those practices visible and, therefore, auditable…” (Sandelowski, 1993, p.2) and in due course the practices and findings become transferable to other situations and contexts. The work of qualitative research is not to produce facts but rather to increase understanding. I kept detailed notes of my interviews including settings, attendees, situation and circumstance, as well as detailed descriptions of the contexts of my interviews. I frequently referred back to the literature to clarify

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\(^1\) I did not have direct patient care responsibilities at the time of their death for any of the patients whose parents agreed to participate in this study.
concepts and themes presented by parents in the interviews. Constant comparative
analysis occurred throughout data collection to look for a pattern of repeating content.

*Instruments and scoring*

Few instruments have been developed that investigate the satisfaction families
have with the end-of-life experiences of their loved ones and even fewer discuss the
family’s satisfaction with the end-of-life care provided in the intensive care setting.
Curtis et al. (2002) developed the Quality of Dying and Death questionnaire as a measure
to evaluate the dying experience. The QODD reflects the premise that it is the
individual’s survivors who remember and judge the quality of dying and death. This
instrument asks family members about their loved one’s end-of-life experience within the
context of the intensive care unit. Curtis and his colleagues (2002) report validity and
reliability of their original 31-item instrument (item and total scores, and reliability
analyses for total QODD scores with a Cronbach’s alpha of 0.89). The tool has not been
used to evaluate the end-of-life experience of children as perceived by their parents
(personal communication Dr. D. Patrick, 1/4/06). The QODD is currently under
investigation for use with pediatric patients in the PICU (personal communication Dr.
Deborah E. Sellers, 1/13/06).

The QODD was further refined and is available as The Quality of Death and
Dying Questionnaire for Family Members Version 3.2A from the University of
Washington (http://depts.washington.edu/~eolcare/instruments/familyqodd3_2.pdf). This
version of the QODD was designed to elicit from surviving family members memories of
the experiences of having a loved one die in the intensive care setting. The instrument has
25 items. Items 1 through 22 have two parts. The first part of items 1-22 ask how often an
experience occurred or whether specific treatments were received. The second part of each of these items and items 23-25 ask the respondent to rate on a Likert scale of 0 (terrible) to 10 (almost perfect) each of these aspects of their loved one’s dying experience. Items 23-25 ask the respondent to rate the quality of dying, the quality of care received from all members of the health care team, and the quality of care received from the patient’s health care team members. The QODD v3.2A score is based on the ratings assigned to questions 1-25. The QODD v3.2A also includes demographic questions and one question aimed to evaluate the burdensomeness of the tool to respondents.

I have taken this tool and rephrased many of the questions to reflect more closely the experience of children dying in the intensive care setting. The Family Systems Committee of the PICU and a parent who had a child die in the PICU several years ago were asked to comment on the phrasing and language used in the Modified QODD. These people also examined the Modified QODD for construct validity. Their input shaped the Modified QODD questionnaire used in this study (see Appendix B). Readers are reminded that it was not the intention of this study to validate the QODD for use in the PICU but to obtain information about parents rating of the quality of their experience of having a child die in the PICU.

Scoring for the Quality of Death and Dying Questionnaire is described as follows. The total score is calculated from 25 items that ask for a rating of certain aspects of care during the last week(s) of life. The scores on the 25 items are added and this number is then divided by the number of items answered to obtain the mean score. The mean score in turn is then divided by the range of possible scores (0-10) and then multiplied by 100 to provide a scale from 0-100. Higher scores suggest a better quality of dying and death.
(Curtis et al., 2002). Note, dividing by 10 and then multiplying by 100 is equivalent to multiplying by 10. In essence, this manipulation merely reports the average rate (or score) out of 100 rather than 10. Indexing to a base of 100 in this case does not simplify the presentation of the results. If anything, reporting the average rating out of 100 while asking readers of the questionnaire to think in terms of an artificial range from zero to 10 would make the ratings have less meaning. Therefore, this researcher chose to record the average score (out of 10).

To provide a summary of parents’ reports of how often some aspect of care occurred parents responses (asked for in the first 10 questions of the QODD) were collapsed into three categories: yes it did happened (that is an aspect of care occurred a good bit of, most of or all of the time), no it did not happened (that is an aspect of care occurred some of, a little bit of or none of the time) or a parent did not know if it happened. Similarly parents’ rating of the quality of each aspect of care included in the modified QODD (all 25 questions) were collapsed into three categories: high (7 to 10, almost perfect), medium (4, 5, or 6), and low (terrible, 0 to 3).

**Procedure**

This study used a qualitative, mixed methods design to investigate the remembered experience of having a child die in the PICU. The interpretive nature of qualitative research yields results that can only be considered subjective. Instead of objectivity, qualitative studies look for confirmability or how well the research findings can be confirmed by others. Lincoln and Guba (1985) describe confirmability as the degree to which the researcher can demonstrate the neutrality of the research interpretations. My “confirmability audit” includes the raw data (transcripts of interviews
with identifying information removed and with my notes highlighted), the Modified QODD survey results, field notes made shortly after interviews, process notes, and personal notes.

Mixed methods research provides robustness to naturalistic inquiry in that it acts as a means to demonstrate the confirmability and completeness of both the methods and findings in qualitative research (Sandelowski, 2000; Tobin & Begley, 2004). Combining a qualitative inquiry with some relevant quantitative measure strengthens the qualitative research findings. In this case, the use of a modified form of the Quality of Death and Dying Questionnaire (QODD) v3.2A (University of Washington, 2002) was used to provide a basis for discussing the quality aspects of end-of-life care. The Quality of Death and Dying Questionnaire v3.2A (see Appendix A) was designed to be answered by families of adult patients who have died in the intensive care unit. Some of the questions are inappropriate for children dying in the intensive care unit in that the deaths of children are rarely anticipated or planned for and as such seldom will children or their families have considered advance directives or funeral plans, two questions specific to the QODD v3.2A. The QODD v3.2A has not been tested in the pediatric population or in patients experiencing sudden death. As such, the items as stated in the original instrument required minor rephrasing to reflect the nature of the pediatric intensive care environment. One of the original authors (Dr. D. L. Patrick, personal communication, 1/4/06) was consulted for and permission granted to adapt the tool for this proposed investigation. For this study, the Modified QODD was examined by three PICU nurses, one parent who had a child die in the PICU several years before, and by comparison of the content of the questions to the aspects of care presented in Emanuel and Emanuel
Accordingly, the Modified QODD has good construct validity. The reader is reminded again that the Modified QODD was used to extend and reinforce the oral interviews.

Addressing the research questions

The first three research questions ask what parents recall of their experience of having had a child die in the PICU, what recommendations they would make to improve this experience for others, and what aspects of care parents consider essential to providing a good death for children in the PICU. The semi-structured interview questions presented in Appendix C address aspects of the parents’ story of having a child die in the PICU: what things they found helpful while their child was in the PICU; what actions or behaviors helped them maintain their family roles; what helped or interfered with being able to develop relationships with care providers; what they remember about the exchange of information with the health care team; what they remember about how well their child’s pain and symptoms were controlled; what systems of support they remember being offered by the health care team and which of these supports they found most valuable as well as what other support they would have liked to have had; if there were other things they would like to have had happen that might have made this a better or more tolerable experience; what things might have been done to make the memories of having a child die in the PICU better; and, finally, what else, if anything, they would like to say about the experience of having had a child die in the Pediatric Intensive Care Unit?

The fourth study question sought parents’ evaluation of the quality of dying and death in the PICU; which aspects they identify as high quality and which aspects of care in the PICU they identify as low quality. The Modified Quality of Dying and Death
Questionnaire (Appendix B) was used to explore parents’ evaluation of the quality of their experience.

Identifying and contacting the sample

Following IRB approval, children who died in the PICU from January 1, 2004 until December 31, 2005, were identified through review of the PICU database. This database records patient admission diagnosis, length of stay, and disposition. The last known contact information (addresses and phone numbers) of their parents/guardians were obtained from these children’s medical records.

Parents/guardians were sent a letter (see Appendix D) inviting them to participate in a research study aimed to discover ways of improving the delivery of end-of-life care to children and their families in the pediatric intensive care setting. This initial contact letter included an information sheet with further details about the study (see Appendix E), a contact information form for them to fill out (see Appendix F), and a stamped addressed return envelope. Parents were requested to suggest a time convenient to them to participate in a semi-structured interview with this researcher to discuss their memories of their child’s dying in the PICU and to complete a survey about the quality of end-of-life care provided to their child.

The primary investigator, a skilled pediatric nurse with many years of experience having patient and parent conversations, conducted the interviews. A second contact was made by mail (including an addressed stamped envelope for their convenience) or email with all parents thanking them for their participation and asking for comments and suggestions to the summarized interview findings that were included. This process of
informing by mail, calling by phone, and then following up reflects the recommendations of bereaved parents as reported by Dyregrov (2004).

**Ethical considerations**

Prior to beginning the interview the purpose of the study, the confidentiality of the interviews, the risks (sadness, relived unpleasant experiences) and the benefits (to have an opportunity to talk of their child; to improve end-of-life care for other children and families) were reviewed with each participant and an informed consent form was signed. All data was collected and analyzed by this researcher, including notes recorded by the research assistant during calls made to recruit subjects into the study.

**Conducting the study**

During the first part of the interview subjects participated in a semi-structured interview directed to obtain information from them regarding their perceptions of the end-of-life care delivered to their child and any suggestions they may have for how care for children dying in the pediatric intensive care unit might be improved. Interviews were audio-recorded, and these audiotapes professionally transcribed. Transcripts were read through, notes were made about recurring content, and parents’ experiences were compared. The contents of these interviews were then compared to the aspects of care present in the modified Quality of Death and Dying Questionnaire to compare what parents recollect about having a child die in the PICU with how they rate the experience.

During the second part of the interview subjects were asked to complete a modified version of the Quality of Death and Dying (QODD) questionnaire; modified specifically in this study by this researcher for the pediatric intensive care setting (See Appendices B and C). The QODD was developed to measure the quality of end-of-life
care provided to dying patients from the perspective of surviving family members. The goal of the Modified QODD is to provide a measure of the degree to which a person’s [in this case parents] preferences for dying and the moment of death are consistent with observations of how the person actually died (Patrick, Engelberg, & Curtis, 2001). Parents’ overall scores on the modified QODD (the evaluation of the quality of the experience) were computed and their ratings examined.

Analysis

Constant comparative content analysis continued throughout data collection. Simply described, in content analysis a researcher looks for the presence of certain words or concepts in some text (in this case the transcripts of the interviews) and then makes inferences about the messages within the text. Content analysis requires breaking down the information presented, labeling these components, setting them into categories or classes, looking at the categories and classes for recurrent patterns and then presenting some interpretation of all of this information.

Each subsequent interview was shaped in part by the preceding interview. The audio-recordings of interviews were listened to, professionally transcribed, the transcripts were read, and then I listened to the interviews while transcripts were read, and then read again. Thirteen of the interviews took place in parents’ homes. Three other participants wished to be interviewed on the study setting campus and arrangements were made for this. During data collection I frequently returned to the literature to clarify (i) experiencing and using my own subjectivity during this study (Peshkin, 1988), (ii) theories about parental loss and bereavement guilt (Miles and Demi, 1984), and (iii) the
processes associated with loss, bereavement, and recovery (Maciejewski, Zhang, Block, Prigerson, 2007).

Member checks

To assure the analysis I made and the conclusions I arrived at were correct, several checks were made. First, a list of the aspects of care that parents identified during the interviews was mailed or emailed to all participating families with a letter thanking them for participating in the study and an addressed return envelope for their comments if they wished to share them. The one parent who replied agreed that these aspects of care reflected her and her husband’s experience. Second, a parent of a child who died in the PICU several years before this study was consulted to comment on a more detailed summary of these themes with parents’ quotes. Third, the research assistant for the study was asked to read notes and selected statements from parents’ to confirm recurring ideas. Finally, field notes and typed transcripts of the interviews were examined again for aspects of care parents consider essential to enabling or providing a good death for children who die in the pediatric intensive care setting.
Chapter 4

FINDINGS

Introduction

The purpose of this qualitative study was to obtain from parents who had a child die in the pediatric intensive care setting their recollections of this experience and suggestions for how this experience might be improved. A semi-structured interview format asked participating parents to recall how they maintained their family roles while in the PICU, how they established relationships with the health care team, how well their child’s comfort was attended to, how information was shared with them, and what types of support they were offered. During the second part of the interview, parents evaluated the quality of different aspects of end-of-life care using the Modified QODD.

Participants

Parents and three grandparents of 14 children agreed to participate. During the interviews, some parents were visibly upset at times and mentioned that they would have liked closer bereavement follow-up after their child’s death. However, when offered they declined my offer to help them find or obtain further grief and bereavement counseling and information.

There were twenty-three participants: seven fathers (one stepfather), three grandmothers (one the legal guardian of the child in the PICU), and 13 mothers (one stepmother). Participants’ ages ranged from 27-65 years old. Twenty-one of these parents had more than high school education. Their children were less than one month to
20 years old at the time of their death. Table 1 provides more detailed information about the sample.

Table 1. Characteristics of Sample

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<thead>
<tr>
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<tr>
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</tr>
<tr>
<td>Range of Ages</td>
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One other set of parents wanted to participate but were advised by their legal counsel not to participate because of a pending lawsuit (their legal suit is not with the hospital or care providers). Eight letters were received indicating parents willingness to participate and providing contact information. Only three invitations were returned declining to participate. Three parents called directly to the researcher but in the end did not participate. Detailed notes were taken during these calls and this information was used for comparison with what parents said during the face-to-face interviews. Nineteen letters came back ‘address unknown.’ Last known phone numbers for non-responders and unknown addresses were called by the research assistant (RA) hired for this task.

The RA was a RN staff member of the study PICU but had not been employed there during 2004-2005. This being the case she was unknown to the parents she called. This
measure was taken to guard against the potential threat of coercion to subjects to participate. The RA called 67 last known numbers. Many of the numbers had been disconnected, at one number there were only Spanish speaking people, and at five numbers the parents declined to participate.

These phone calls identified nine other parents who said they were willing to be subjects in this study. Many of these parents spoke at length on the phone, again up to 45 minutes, with the RA and expressed much enthusiasm in being able to participate. They provided contact numbers and times to call but were subsequently unavailable when the researcher called. Three attempts were made to contact these numbers. Due to the sensitive aspects of discussing the death of a child, phone messages were not left. In the end, the calls made by the RA recruited the parents of six other children who had died in the PICU. All six of these participants were included in the initial mailing. None of these letters came back as undeliverable. Only one of these families reported never having received the information about the study.

The participants in this study were assigned fictional names to protect their anonymity and to personalize their stories. The initials of these fictionalized names were also used to identify individual parent responses on the Modified QODD. For interested readers the Modified QODD results are presented in Appendix H.

The framework for this analysis is adapted from Emanuel and Emanuel (1998). This framework suggests that how survivors define or determine a ‘good death’ is based on their evaluation of their ability to maintain family roles, the availability of information, their evaluation of the effectiveness of pain and symptom control and the systems of support that were offered or available by the health care staff. Review of the
transcripts and the results from the Modified QODD suggest several aspects of end-of-life care in the PICU are either helpful or needful of change. The research questions are addressed under the following headings: experiences remembered (maintaining family roles in the PICU, establishing relationships with health care providers, information exchange with health care providers, comfort and symptom control for their child, systems of support offered); parents’ recommendations; essentials for providing a good death in PICU; and parents’ evaluation of the quality of dying and death in the PICU. The experiences reported by the parents in this study are presented below.

Throughout the interviews there was one consistent and repeating theme. Parents spoke often about what they needed to know, how they would like to have been told, whether they received the information they needed or wanted or how they might have been told things differently. The theme of parents needing to know and desiring information exchange has been labeled communication. Communication is the imparting or interchange of thoughts, opinions, or information. Merriam-Webster’s Online Dictionary defines communication as a process by which information is exchanged between individuals through a common system of symbols, signs, or behavior. Communication involves contact, exchange of ideas, interaction, transfer, consultation and transmission between or among two or more people. In the interviews parents reported that some level of communication was absent in every aspect of care they were questioned about. The theme of communication is discussed within the findings for each of the four research questions.
Experiences remembered

Maintaining family roles in the PICU

When a child is admitted to the intensive care unit, the ability for parents to carry out or maintain their usual parenting role is frequently impeded by the critical health care needs of their child. Most if not all of their parenting responsibilities must be surrendered to the intensive care unit staff. This often reduces their parenting role from doing for their child to observing others do for them. For parents this can be frustrating.

Charlotte\textsuperscript{2}, the legal guardian to her grandson, expressed frustration that some members of the PICU team did not listen to her and dismissed what she had to say about her grandchild:

“But I had told them point blank, I am his grandmother, he holds his breath until he turns blue…. I mean I’ve lived with this kid for three years…And I reached over and I turned his position and his respirations went right back up… They need to listen to parents more, or the grandparents.”

Usually, though, even if their child’s condition and needed medical equipment prevented their ability to perform usual childcare, parents felt they were encouraged to participate. This is reflected in the experience reported by Vivian, the mom of one teenager:

“Yes, I mean…, if you wanted to give your child a bath, you could and if you didn’t want to, they would do it. If you wanted to, he had so many tubes though. He had stuff everywhere so it was kind of hard but anything you wanted to do, if you wanted to rub his feet, I mean, they let you be the parent… as much as you could be in a situation like that.”

\textsuperscript{2} Parents have been assigned fictional names to personalize their stories and identify them to the reader. The first initial of these names also identifies that individual participant’s responses on the modified QODD (see Appendix H).
Other parents recalled being encouraged to participate in care and maintain their parenting roles. Nick and Mary were parents to an infant with a serious heart defect. Mary said:

“They would tell us, you know, just massage her arms and keep them open and move them around … and that’s kind of how I would play with her, you know? When she could I would just kind of move her arms and try to rub her feet and stuff. Cause, you know, there’s not – there – with her there wasn’t a lot of room that we could touch her, she was pretty much filled up from head to toe.”

Another aspect of maintaining their parental role was being able to remain with their child. Being present with their children in the PICU let parents reassure or be reassured by their child, get to know them, watch over them, and protect them. Being able to maintain a family presence with their child meant much to parents and was something they were proud they were able to do for their child. For example, Nick and Mary considered their ability to be present helped them establish a relationship with their baby and foster feelings of being parents. Being able to establish a parenting role with her daughter was especially important to Mary: “We were really lucky to get to hold her and know her, and … breastfeeding her… ‘cause I felt like that could be a bond for both of us, and it was at the beginning.”

Remaining present with their child reduced parents’ anxiety. Olivia and Quinton recalled being able to have someone be present with their school age daughter at all times. Olivia reported:

“That we were allowed to be with her almost the whole time was very important… and we never felt any pressure at all to leave… I know it meant a lot to [our child] for us to be there. It was so hard…, it would have driven me crazy if we had had to leave and only come in every few hours or something.”

In contrast, parents who were unable to be present or were unable to get all of their family members gathered to say goodbye to their child indicated that this was and
remains difficult for them to accept. Linda was one of the parents unable to get back to the hospital to be with her child when she died. In talking about that night, Linda wished she had not given in to her husband’s and family’s requests for her to go home. She remains disturbed and angry with them that she was not with her daughter when she died. She recalled feeling that she knew her baby was not going to make it through this night and that her family was “clueless” in not acknowledging her need to stay. For Linda, staying with her daughter “would have been better than to just come back and pick up a plastic bag of some items.”

For Allen and Una, parents to an older teenager, not being able to get everyone to the hospital before their son died still disturbs them. Of special concern for these parents is how their daughter “still hates that” she did not get to tell her brother goodbye. Sometimes the PICU visiting rules interfered with parents’ ability to pray, be with their child, and grieve with their family. In a phone conversation one mother reported how horrible it was for her to be asked to leave at shift change. Her daughter did not survive long after her surgery. This mom said she knew the rules, knew the reasons behind them but that these rules needed be more flexible:

“But in the PICU… they only let two people in the room. I mean my baby was going for surgery and my mom and dad wanted to be with us to pray and be together … but the staff would only let two of us in. It really made it hard for us … especially when she was dying.”

Charlotte, appreciated being able to hold her grandchild, but she wished the nurse had come back in to check on her instead of leaving her alone waiting for her family to come be with her:
“I mean I loved holding him and stuff but it’s really not a time that you really need to be by yourself… we put a gown on him and she set him in my lap and then nobody came back in the room …it was just me sitting there holding him.”

Communication about parental roles

Throughout the discussions about maintaining family roles parents talked of wanting to be more involved with the care of their child. These parents wanted instruction in how to provide care for their child despite the machinery and accoutrements of the intensive care environment. In maintaining their family roles the theme of communication recurred in parents’ expressions of wanting to be more informed and be informed earlier of what they could do to remain providers of care for their children. Terry, Vivian’s ex-husband, said: “We need to know and be told what opportunities there are … even something like I said just as simple as: Can I still whisper in his ear? Can I still … wash his face?”

Establishing relationships with health care providers

Developing relationships with caregivers was very important to the parents in this study. Having consistent caregivers allowed parents to feel their child was cared about and not just being cared for. Parents were often able to name or describe many of their child’s care givers and stated how readily these members of the team kept them informed of what was happening or was going to happen and why. The extent of the relationships parents formed with the health team seemed centered on the communication they felt they received. Most parents and grandparents in the study reported developing excellent relationships with the different members of the health care team in the PICU especially nurses and respiratory therapists. They expressed pleasure at having consistent caregivers (nurses, respiratory, chaplains, doctors). Terry described how having consistent caregivers for his son was reassuring:
“That was his team. They had shifts so almost three or four nights a week the young
man would be there and three or four days a week this same young woman would be
there and … I was very glad to see the same person when I come in. Then I just
didn’t feel like they were assigning nurses to whoever’s needed that time that they
have actually knowledge of his special symptoms.”

Yet, relationships with the PICU health care team were strained for some parents.

For one parent the first memory she shared was her feeling that the seriousness of her
daughter’s condition was dismissed even before the doctor examined her child or spoke
with her. Helen recalled this incident:

“In walks Dr A with Dr B and I’m in the crib with my daughter and she is alert and
not grunting anymore… But his, first words out of his mouth was ‘What is she doing
in here?’ with kind of an attitude… He just looked at her from across the room with
this, what-is-she-taking-up-my-bed-space-for?-she-doesn’t-look-sick-enough kind of
attitude.”

Another parent was uncomfortable with how a nurse she had not met before spoke to
her about placing an intravenous line in her child’s scalp. The nurse had been asked to
assist her child’s nurse. Mary said:

“There was one nurse that came in, and she pretty much broke it down that ‘I know
this is hard, but you have to realize that if we don’t get this anywhere else we have to
go through her scalp.’ And, I’m like, you know, that was kind of the wrong approach
to be taking me. Maybe you can come back and do this when I’m not here, but to
present it to me like, you know, you gotta go ahead and go right into her head, this is
not what I want to hear right now. I was very upset. I told [husband] I don’t want this
nurse back in her room, you know? I – I did not feel very comfortable with her just
blurted it out the way she did, and it made me very uncomfortable.”

Effect of communication on relationships.

Being kept informed and being asked to participate or contribute information to the
team affected these relationships. The way parents were communicated to about their
child was crucial to this. Many parents reported that how they were spoken to influenced
their feelings of how their child was being cared for. Being able to talk with the health
team about their children’s interests or their own plans helped parents form relationships
with the health team. When parents were not provided the opportunity to talk with the health care team or felt that communication was lacking they reported not being able to establish satisfactory working relationships with the caregivers. What interfered most in establishing and maintaining relationships with the health care team concerned aspects of communication – having to restate information that was already in the medical record, having infrequent contact with their child’s physician or surgeon, or having the medical team come in and not address their child by name or even appear to know their child’s name. For Linda, the team not knowing and not referring to her daughter by name made her feel that both she and her daughter were unimportant and they were wasting the team’s time:

“They don’t see that the child’s going to survive, so they’re kind of avoiding that room…. Where I think they should be coming in and talking, more conversation, instead of making you feel like, okay, ‘Well she’s going to die anyway, so we don’t need to waste our time there.’ You know, that was the feeling… That’s how I felt.”

Information exchange with health care providers

During these interviews, parents often mentioned, discussed and referred to what they were being told and how information about their child was told to them. Few parents spoke about being asked for information about their child or their opinions about proposed treatments. In one interview the parents mentioned no less than 200 times the importance of how information was shared with them. These parents repeated often that they wanted “communication,” wanted to be “told”, wanted to “discuss,” “know,” “say,” and “tell” about their child. Una felt that the best information exchange she had was with one of the nurses who gave them information about what to expect:

“This was a serious situation and instead of someone telling me well we might can do this and we might can do that, she didn’t say that. She said this is what we need
to do and this is what’s going to happen and when she told us about the ventilator
and we told her no, well she gave us, told us, you know, this is going to happen.”

Parents spoke about the communication that happened or did not happen or that they
wished had happened. Usually the parents participating in these interviews were referring
to how much communication or interaction or the number of times they saw or spoke
with the medical team, specifically their child’s doctor or doctors. In other cases parents
mentioned how they were not provided enough opportunity to question information they
received about their child’s condition or care. Helen recalled being present during rounds
and hearing information that she did not understand:

“They were doing rounds and I was waiting out side the room for the X-ray to be
finished… off starts this diatribe of a lot of stuff I didn’t understand, but the stuff I
did understand was very scary… And I just stood there listening to it going, oh, good
Lord. And so then at the end they started to walk away. And I said, excuse me, I
have a question about that. Can you please explain what you just said? The Dr. says,
oh we have to finish rounds. We’ll come back later and answer your questions…
And then they called in the pulmonologist… And her belly started to grow again…
like in front of our eyes… And then we’re trying to find my husband because they
say we may have to do surgery to see what’s going on…and somebody was
explaining the surgery and I’m signing consent… at no point did they say she could
die in this surgery. They never said that.”

Several parents reported receiving conflicting messages. For Vivian, it was difficult
at times to sort through all of the information from all of the different medical teams
involved with her child:

“But it’s just like sometimes you didn’t like know stuff and the one thing is you do
have so many different doctors coming in… and it’s like … one doctor tells you one
thing and another doctor tells you another thing and it’s like, it’s so much and all you
really care about is your child and you’re just trying so hard to figure out to do
what’s right.”

Nick found that the information he and Mary received from the medical team was
often confusing and left them feeling even more uncertain about their daughter’s
condition. :
“So I was like what are you saying, you know? What is – what are you telling me right now? I mean, are we at the point where she’s ready to go and we have to decide, and what are you telling me? And he was still kinda like well, we need to just wait and see for a little while, and it’s almost like he didn’t want to make the decision for us… and he sat us down and told us everything. And, he said, ‘I don’t want you to make a decision right now.’”

Conflicting or unclear messages delayed parents understanding that their child was dying. In some cases, the vagueness of information presented to parents interfered with their making plans and arrangements for their family members to be present at the time of their child’s death or in time to say goodbye.

Other parents spoke of how their decisions were not readily accepted by the medical team. Charlotte commented on the harshness in the tone of voice and the disregard for her opinion of what was best for her child:

“And when I said no the lung doctor informed me [when she refused a tracheostomy for her son] that I was committing him to a uh… um… horrible death with a lot of pain… You know, so they need to pick their words a little better.”

Paula’s daughter died less than an hour after life-supporting treatments were withdrawn. She recalled the medical team as being unrealistically optimistic about her daughter’s condition:

“They insisted that she was a very good candidate for a normal life and everything was going to be fine although she was never able to make it out of the unit. She was never able to come off the ventilator. She was never stable for more than twenty-four hours… The longer they could keep her alive then the more successful they were … and that may be true in some ways but it’s also torture for the child and family.”

Parents had been used to providing all aspects of care for their child but were often forced by the seriousness of their child’s condition to relinquish some and usually most of their normal parental duties to the ICU health team. In the PICU, parents wanted to be instructed on how to remain involved as a parent with their child. Not receiving information and instruction from their children’s nurses about how to carry out or adapt
their parenting duties left parents unsure of the level of involvement they could assume in providing care for their child. Describing wanting to be involved in the hands on care with his child, Terry reported how he didn’t know what he might be able to assist with and didn’t know how or who to ask. Eventually he was invited by a nurse to help in turning and changing his son; he commented:

“I was glad to do that. I felt otherwise I’m just sitting there watching someone do this to my son. If there’s stuff, like I remember his hands getting so chapped, and lips, you know… I guarantee it would have been done as good if not better than by a nurse cause we’re sitting there waiting to do it… I bet you’d be surprised at how many people [parents] would be willing to do whatever [for their child].”

Some parents did experience a fair amount of information exchange in the PICU. However, their need and search for information continued. Mary described:

“I was always wanting to know what was going on and making sure when they came in to do echocardiograms, any kind of x-rays… even the drugs they were administering I wanted to know what was going in, why it was going in.”

At times families wanted more information but did not know what information to ask for or who to ask it of. Vivian suggested that there be some regular follow-up with parents in the PICU to check their understanding of what they were told or whether they might need more explanation or more information:

“… it seems like if you could just have a little bit more information… But it’s like maybe they could tell you that stuff and then tell you again to make sure it sunk in. Or maybe have someone go over it with you again because I didn’t know.”

Often parents talked about how they supplemented or clarified the information they received. Parents also reported having to work at getting information about their child’s condition. Nick reported that he and Mary “were both on the internet … looking for every surgery that’s ever been performed, trying to know all the possibilities; everything that’s possible, outcomes, future life, I mean, just overdrive the whole time.” Frequently, when
the PICU team shared information it was presented quickly and parents did not always get the opportunity to ask questions. When this happened, they were left to use other resources and supports to get the information they needed. Helen remembered the PICU team not being able to get back to her quickly enough: “So I went and called Dr. C… and I called everybody I could on the fifth floor to come down and help and please explain this to me and to get me some answers…”

At times the amount and type of information parents received left them feeling even less informed. Sometimes they were presented with too much or too little detail to understand fully what was being conveyed and this left parents feeling overwhelmed. Mary, whose child was being investigated for a genetic cause to her heart defect, describes this:

“… the genetics team, they are just like so smart anyway and they start throwing all this stuff, and I’m like oh my God. Like I can’t handle all this right now. I couldn’t really understand it or grasp it, so later he’d [referring to husband] have to break it down to me just so I could understand what they were talking about, you know?”

Rose, grandmother to a teenager, described how in general parents and families are unfamiliar with their child’s condition and need to work at understanding the information they are given:

“… the majority of people who come in there with children … have no knowledge of any kind of medicine at all or they might know a little bit but the majority of people don’t know anything about the disease. We looked up everything we could on the computer and I’m a nurse and I still was lost.”

Influence of communication on information exchange

Parents reported wanting to understand and to know what was happening with their child. Confusing or conflicting information was anxiety provoking. To reduce their anxiety and uncertainty parents frequently consulted other sources, mainly the internet,
for clarification of what they were being told. They wanted information from the PICU team concerning their child’s condition, treatment plans, and prognosis to be both realistic and clear. As Gloria relayed: “That’s the one thing I wish they would have stressed more to us… it doesn’t seem real when they’re talking and telling. They should stress more … We didn’t think that there was a big chance of him dying ‘cause they told us … ‘It’s just a surgery we’ll have to do.’”

_Pain and symptom control for their child_

Parents expressed how important it was to know their child was kept comfortable. They remembered staff educating them about the treatments and medicines being used to relieve their child’s pain and control his or her symptoms. Mary recalled wondering how all the treatments and equipment was affecting her daughter and asking whether she was experiencing pain:

“When she went on that ECMO they had to use tranquilizers and stuff to make sure that she wasn’t moving. And, um, the other thing we were worried about, you know, the possibility of the pain … and her remembering the pain or anything like that. And, they explained to us the drug processes and that … that was important for them and us I think. They would tell us she is -- she is comfortable, she’s not in pain. Because, when you looked at her, you know, it pained us. And, it looked painful.”

Most of the parents in this study reported their child’s pain or other symptoms were controlled. They also recalled being reassured by the manner the health care team performed physical care. Parents were able to describe instances when pain and symptom control were provided for their child and how they were reassured their child was comfortable. Mary sums up this experience:

“She was really nice and she was really good with her, and I appreciated that too, that she was easy with her… I hated to come in and see somebody moving her around, and I guess it probably would pain me more than it would hurt her [child], but I mean, she was just really gentle and she talked to her, you know, while she was doing it, and that kinda helped me and made me feel more comfortable.”
Even when they were unsure if their child was experiencing pain, parents reported that they did not see any signs that their child was in pain. Parents of older children did not remember them complaining or exhibiting signs of pain:

“No, I don’t think she was in no pain. I could tell when she was in pain. She’d go to whining and moaning… the only way I could tell, you know, she was in pain, she would start whining or crying. That’s the only way I could tell. They kept her…. not all the way out, but you know, in and out once in a while. But right there, at the last, they kept her sedated. After the doctors talked to me, they told me that they wanted to take the vent off of her, and that’s when they started giving her more…. They didn’t want her to… the nurse said she didn’t suffer.”

Other parents recalled their child being uncomfortable at times but saw that this discomfort was treated quickly. Only one set of parents in this study reported their son being in pain while he was in the PICU. Allen and Una’s son had been admitted in respiratory distress at the end stage of his chronic illness. These parents recognized that treating his pain might have worsened his respiratory distress but they did not understand why his pain could not be treated. There seemed to be a lack of understanding among these parents and the PICU team about their child’s condition and the goals for his treatment:

“He was in a lot of pain. They wouldn’t give him any thing and I think it was more because they were scared that it may do something worse. But there again, no one ever discussed that with us and when we tried to get him something cause he was hurting. I mean he was hurting. They would never give us any reasons or anything why they wouldn’t do it…. until the time he died, then they started pumping him with morphine.”

Communication about pain and symptom control

The comments parents made throughout the study reflected their concern that their child be comfortable. Parents talked about how they were confident that their child’s pain was being taken care of and how they could recognize this in their child’s behavior. They
were also reassured by the information the health care team shared about the medications and treatments their child was receiving to control for pain. Knowing that their child was not in pain was comforting to parents. Betty considered her child was comfortable because he was calm and still:

“They were very good about coming in on time… and… he didn’t seemed stressed at all… I’d hold his hand and mess with his hand, you know. But he didn’t seem stressed at all.”

*Systems of support offered by the health care team*

Most parents recalled having ready access to the hospital chaplain and the comfort they got from being able to pray or have their child baptized. Parents also listed how important having contact with the social worker was in helping them make arrangements to be able to stay with their child. For parents with very limited resources this support was greatly appreciated. Wendy recalled:

“They had support, I mean, they were there if I needed to talk to ‘em. And the social worker and the chaplain was in there, and the chaplain was good… I mean, she was good. In fact, I knowed something’s wrong when I went in... in the room, was talking to the doctor, and that’s when we all got around the table, and he give me his card and said, if there’s anything that they could do, for me to call and let ‘em know. That they’d be more than glad to do what they could.”

For Linda, who recalled little personal contact with the medical staff and limited relationships with the other staff, the chaplaincy was the only support she recalled:

“Just the Chaplain…. The Chaplain was there…. [Nobody] there could really answer any questions that I might have had other than the doctors when they came in occasionally. And I don’t think they wanted to say too much. It just seemed like nobody ever wanted to say too much.”

Parents also mentioned that having access to the overnight family rooms and Ronald McDonald House made it easier for them to stay close by their child. Mothers of young infants who were breastfeeding found the availability of the mechanical breast pump
supported them in maintaining their role as new mothers. Parents who did not recall any specific modes of support being offered did say that they felt they got what they needed.

It was apparent in the interviews that individual families required different kinds and varying degrees of support. Most parents recalled having the support they needed. Wendy remembered how well support was provided:

“Well, like I said, they all come in and talked. And I had all my family there, you know, to help with support and stuff. And anything I needed or wanted, they would... they were right there. In fact, that day we went, the social worker come and give me a … check and I went downstairs around the corner somewhere, and they cashed it for me, so I could come back to forth at Chapel Hill. All of them was good. I couldn’t ask for nobody no better…. And then they seen that we got a room. There was five of us, and we went to Ronald McDonald House. And they said that five wasn’t allowed to stay, but they went ahead and made room for us in the Ronald McDonald House.”

Interestingly, parents did not mention nurses or nursing when asked about support systems offered in the PICU. This might suggest that families did not find nurses supportive. However, without fail each family mentioned how wonderful they found the nurses, how great the nursing care provided was, what great relationships they formed with certain nurses. When parents are asked about support systems, they may believe that nurses and nursing care are not considered within this category. For parents, nurses and nursing care seems to be something different and separate from support systems.

Communication regarding systems of support

Most parents reported that they experienced good support from all members of the team and had few suggestions to make about what other types of support might have been helpful. They felt their needs were identified and attended to. However, the few parents who did have suggestions for how providing support to parents could be improved focused on the need for more direct and available communication about their child’s
condition during their stay in PICU and about how to care for themselves after their child had died. These parents wanted to be kept aware of the progress of their child’s surgery and suggested that someone should be available in the PICU waiting room to inform parents of their child’s condition during procedures, tests and surgery. Parents also wanted more information about grieving, bereavement and available counseling after their child died. About half of these parents suggested that a good support would be some kind of follow up to check on them and how they are coping with their loss. Nick and Mary would have liked to have had systems of bereavement support be identified for them prior to their leaving the hospital and that follow up contact had been made to check up on them and how they were coping. Fiona would have liked to have been given a listing of bereavement support services available in her town.

Parents’ recommendations

Parents recommended that communication be improved and increased both between the team and the parents but also among the different health care team members. Parents felt that more communication and more information about the seriousness of their child’s condition sooner in the course of treatment might have led them to make different decisions or to have decided earlier about their child’s treatment course. Parents would have liked to have been told more directly that their child was dying or was expected to die soon so that they might have made other arrangements. These other arrangements included being able to take their child home for some time, to do some last thing their child had wanted or requested, or to have made some kind of family memory.

Also recommended is that some system of follow-up with the parents of children dying in the PICU be implemented. Parents in this study wanted to be called, written to,
checked up on, and asked about their coping. They wanted to have been told what to
expect after their child died – what feelings they might have, how they might react
afterwards. Even after more than a year parents wanted to talk about their child and their
experience. As Nick related:

“And… and there’s a lot there. I mean, for fathers and especially mothers, you
know? That connection with your child, and losing that child. There is – it needs to
be dealt with psychologically, and people need to express their feelings, and to go
through the grieving process and don’t need to be shut down… Maybe after a phone
call, send out a package with all types of information especially about the grieving
process.”

Follow-up that does not address a parent’s individual needs can be counter
productive. For example, Linda considered what little follow-up she was provided
impersonal and blatantly lacking in any knowledge of her or her child. She regarded most
of the follow-up she did receive as meaningless:

“They sent out her heart pillow with all these signatures on it but this was after she
died and I didn’t recognize any of the names… The things that were signed, well
obviously this was done as a second thought… they didn’t apply to my daughter.”

Parents recommended that there be more follow-up with parents who have lost a child
to make sure they are doing all right or finding good resources to help deal with the
memories and stress of remembering the time spent in the PICU and having lost a child.
As well, parents thought it would be beneficial if they could be informed of the common
signs and symptoms of grief and grieving.

*Essentials for providing a good death in PICU*

The parents in this study made many and varied suggestions for improving end-
of-life care for parents of children dying in the PICU that could greatly affect how
parents experience and remember this. These suggestions ranged from simply making the
PICU environment more comfortable and welcoming to allowing parents more time at
the bedside after their child has died. However, the one common suggestion was that
communication be improved: communication of bad news and style of communication
were specifically addressed by parents in this study. Parents wanted communication from
the health care team to be direct, accurate, and realistic. As Mary succinctly put it: “Don’t
sugar coat it with me when you’re talking about my boy.”

Parents in this study also had other aspects of care and of the experience of having
a child die in the PICU to share. Specifically parents recalled how different the PICU
environment is, their experience of grief, their feelings of guilt and regret, how they were
making memories of and paying tribute to their child, and their need for follow-up. What
follows is a discussion of these items.

*Things are different in the PICU*

Parents of children coming into PICU from within the hospital were uncertain of
their role in the PICU and not always aware of the escalation in the seriousness of their
child’s condition. On having her child intubated Helen said:

“And I was like, well, they’re doing that to help her breathe, like I didn’t clue in that
this is a dire situation… Then [one of their nurses from the floor] walked in and was
like, ‘Good God!’ you know, because she hadn’t seen us in several days. I should
have clued in right there.”

Terry likened coming into the PICU as stepping off of a spaceship into some alien world
both foreign and frightening:

“It’s like oh my God he’s moved into the PICU… When the doctor comes by it’s
now more scary than it’s ever been… It’s like taking a huge step, a bigger step than
you think it’s gonna be… You need more monitoring and everything but the reason
you need that is because this is really happening… Your condition has worsened…
There is nothing familiar. There’s nothing homey. There’s nothing, it’s just a
different kind of place.”
Grieving

Parents in this study continue to have very strong feelings (tears visible, wiping eyes and nose, having a quivering chin when talking, openly crying, speaking of post traumatic stress syndrome) about their loss and it is very obvious that they continue to miss their child deeply even though it has been more than a year after he or she has died. They were aware that their grieving was prolonged and wanted to know what normal grieving was supposed to be like. Parents invested much time and energy in attending to their child throughout the length of their illness regardless of whether the illness or condition lasted for a short or a prolonged time. When their child died these parents faced emptiness in their routine and wondered how they would continue. As Fiona recalled:

“And the next day I think was harder on me, because I felt all the pressure I had and all the feelings I had, I was like, now what do I do? You know? I’ve been there for her. I’ve been there every day. Now what do I do?”

Guilt and regret

Several parents made comments that suggested they continue to feel some guilt at having their child die. This occurred most often with parents who withdrew life-supporting technologies or who were unable to be present as their child died. Other parents regretted that there might have been something they could have done that may have improved their child’s last days. Terry spoke at length about how he wished he had realized how close his child was to dying before he was transferred into the PICU. He regretted not having been able to fulfill his son’s requests to come home:

“You know, he said ‘I want to sit in my room one more time. I want to see my livestock… I want to ride my four-wheeler and sit in my car one more time.’ And if we knew that… within seventy-two hours he was actively dying… I just wished he’d been sicker or visibly sicker to me before he moved into the ICU. Before then if we were going to move him there knowing that he was probably not going to come out, there was just several things we wished we had gotten to let him do.”
Others mentioned how they should have been more aware of the signs and symptoms in their child and more understanding or receptive to the informational clues that in retrospect they remember being given about how sick their child was.

Making meaning and paying tribute

Parents also spoke of the meaning their child’s life has had and continues to have. They expressed interest in participating in this study to continue to give meaning to their child’s life and to share their experience to make things better for others. It is important for parents to share how they made meaning of their child’s life for this allows them to hold on to their relationship with their dead child (Davies, 2004).

I was shown pictures, websites, tributes, and markers of these parents’ children. One mother during our interview was wearing a button pin picture of her daughter. Most parents had pictures of their child openly displayed in their homes or pulled out photos and photo albums to show me. One parent described bringing her daughter home to hold and rock after she had died so that she would become and remain a part of the spirit of their home. Several other parents donated organs from their child.

Parents of infants who died in the PICU expressed a desire to have taken more pictures of their child especially prior to their surgeries or treatments. One couple brought out their baby’s picture book in which the photos capture their child’s short life. The first picture shows a beautiful and extremely normal looking baby cuddling in Mom and Dad’s arms. In the next few photos, the baby is pink and alert and many family members are pictured holding her. The next few pictures show a progression and escalation of medical treatment and technology. The final picture captures the baby with eyes and
chest open. Photographs provide both memory and meaning to parents’ experience of their child but pictures may also serve as stark reminder of all their child went through.

Most parents gave examples of the meaning their child’s life and death had and the contribution their child has made or was able to make on their dying. They mentioned the actions they take or would like to take to continue their child’s legacy – being a representative to other parents of children with congenital heart disease, remaining in contact with their child’s specialists, sponsoring fund-raising events, providing real information on a website for other parents.

**Parents’ evaluation of the quality of dying and death in the PICU**

Parents’ evaluation of the quality of experiencing their child’s death in the PICU was obtained by using the Modified QODD. Parents’ scores from this tool suggest that for the most part the quality of the dying and death for children in this PICU was acceptable to them. The range of scores was 4 to 10, the mean score was 7.25 (median 7.8) and the standard deviation of scores was 2.11 (95%CI ± .91). The summary of results from the Modified QODD survey is presented in Table 2. This table reports the frequency of the two variables asked about in each part of the questions, that is, whether or not an aspect of care occurred and how this aspect of care was rated. Each cell of the table (each individual number) indicates the number of participants whose answer to the first part of the question matches the column label and whose answer to the second part of the questions matches the row label.

The reliability of an instrument is usually analyzed using a Cronbach’s alpha. However, this analysis can not include items with missing data and many of the Modified QODD surveys had missing values for two or more items. To enable a calculation of
Cronbach’s alpha, questionnaires with missing data can be handled in several ways; items with missing values can be discarded or an estimate can be used to replace missing values (Raaijmakers, 1999). Replacing missing values with estimates increases the Cronbach’s alpha. If too many of the questions are replaced with an estimate, the Cronbach’s alpha is inflated and provides a less useful indicator of a tool’s reliability. In this study, the decision was made to include in the reliability estimate questionnaires that had no more than one missing value. This left only 12 usable questionnaires. In an effort to increase the number of usable surveys, the questionnaires were examined for patterns in items with missing values.

During survey analysis it became evident that many parents had no comment or rating for the item discussing dialysis – few of the children in the study were on dialysis at the time of their death. Similarly, few parents commented on or rated the item dealing with whether or not they or their child had been able to clear up bad feelings prior to their dying. The extreme young age of most of the children and the relative youth of the other children in this study is suggestive of these children not having had time in their short life to have made bad feelings. Dropping these two items from the questionnaire increased the number of usable questionnaires by two. Cronbach’s alpha was run on the 14 questionnaires with no more than one missing value (3 questionnaires had one missing value) and this missing value was replaced by the mode of the responses to the other 22 items. The Cronbach’s alpha is 0.929. A Cronbach’s alpha greater than .9 is one indication that all of the items may be asking the same thing. However, seeing that only slightly more than half the questionnaires were able to be included in this calculation, the
The credibility of this alpha is suspect. The reliability of the Modified QODD in this study is questionable.

<table>
<thead>
<tr>
<th>Question</th>
<th>No</th>
<th>Yes</th>
<th>DK/NR</th>
<th>Rating</th>
</tr>
</thead>
<tbody>
<tr>
<td>1a. How often did your child appear to have his/her pain under control?</td>
<td>3</td>
<td>12</td>
<td>0</td>
<td>High</td>
</tr>
<tr>
<td>1b. How would you rate this aspect of your child’s experience in the PICU?</td>
<td>3</td>
<td>1</td>
<td>0</td>
<td>Low</td>
</tr>
<tr>
<td>2a. How often did you feel you had control over what was going on with your child in the pediatric intensive care unit?</td>
<td>2</td>
<td>10</td>
<td>0</td>
<td>High</td>
</tr>
<tr>
<td>2b. How would you rate this aspect of your child’s experience?</td>
<td>6</td>
<td>0</td>
<td>0</td>
<td>Low</td>
</tr>
<tr>
<td>3a. How often was your child able to be fed or feed her/himself?</td>
<td>3</td>
<td>0</td>
<td>0</td>
<td>High</td>
</tr>
<tr>
<td>3b. How would you rate this aspect of your child’s experience?</td>
<td>8</td>
<td>2</td>
<td>0</td>
<td>Low</td>
</tr>
<tr>
<td>4a. How often did your child appear to breathe comfortably?</td>
<td>3</td>
<td>6</td>
<td>0</td>
<td>High</td>
</tr>
<tr>
<td>4b. How would you rate this aspect of your child’s experience?</td>
<td>6</td>
<td>0</td>
<td>0</td>
<td>Low</td>
</tr>
<tr>
<td>5a. How often did your child appear to feel at peace?</td>
<td>1</td>
<td>10</td>
<td>0</td>
<td>High</td>
</tr>
<tr>
<td>5b. How would you rate this aspect of your child’s experience?</td>
<td>5</td>
<td>0</td>
<td>0</td>
<td>Low</td>
</tr>
<tr>
<td>6a. How often did your child appear to be afraid?</td>
<td>9</td>
<td>0</td>
<td>0</td>
<td>High</td>
</tr>
<tr>
<td>6b. How would you rate this aspect of your child’s experience?</td>
<td>6</td>
<td>1</td>
<td>0</td>
<td>Low</td>
</tr>
<tr>
<td>7a. How often was your child able to laugh and smile?</td>
<td>7</td>
<td>1</td>
<td>0</td>
<td>High</td>
</tr>
<tr>
<td>7b. How would you rate this aspect of your child’s experience?</td>
<td>7</td>
<td>0</td>
<td>0</td>
<td>Low</td>
</tr>
<tr>
<td>8a. How often did your child appear to keep his/her dignity and self-respect?</td>
<td>13</td>
<td>0</td>
<td>0</td>
<td>High</td>
</tr>
<tr>
<td>8b. How would you rate this aspect of your child’s experience?</td>
<td>3</td>
<td>1</td>
<td>0</td>
<td>Medium</td>
</tr>
<tr>
<td>9a. How often was your child able to spend time with family members or friends?</td>
<td>0</td>
<td>15</td>
<td>0</td>
<td>High</td>
</tr>
<tr>
<td>9b. How would you rate this aspect of your child’s experience?</td>
<td>2</td>
<td>0</td>
<td>0</td>
<td>Medium</td>
</tr>
</tbody>
</table>

| 9c. How would you rate this aspect of your child’s experience? | 0  | 3   | 0     | NR     |

Note: DK= do not know, NR= no reply
Rating is on a Likert scale, Low = 0-3, Medium = 4-6, High = 7-10
<table>
<thead>
<tr>
<th>Question</th>
<th>No</th>
<th>Yes</th>
<th>DK/NR</th>
<th>Rating</th>
</tr>
</thead>
<tbody>
<tr>
<td>10a. How often did your child spend time alone?</td>
<td>14</td>
<td>1</td>
<td>0</td>
<td>High</td>
</tr>
<tr>
<td></td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>Medium</td>
</tr>
<tr>
<td>10b. How would you rate this aspect of your child’s experience?</td>
<td>2</td>
<td>1</td>
<td>0</td>
<td>Low</td>
</tr>
<tr>
<td></td>
<td>3</td>
<td>0</td>
<td>0</td>
<td>NR</td>
</tr>
<tr>
<td>11a. Was your child able to be touched or hugged by his/her friends,</td>
<td>0</td>
<td>14</td>
<td>0</td>
<td>High</td>
</tr>
<tr>
<td>family, others?</td>
<td>1</td>
<td>3</td>
<td>0</td>
<td>Medium</td>
</tr>
<tr>
<td>11b. How would you rate this aspect of your child’s experience?</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>Low</td>
</tr>
<tr>
<td></td>
<td>0</td>
<td>3</td>
<td>0</td>
<td>NR</td>
</tr>
<tr>
<td>12a. Were all of your child’s health care costs taken care of?</td>
<td>2</td>
<td>15</td>
<td>0</td>
<td>High</td>
</tr>
<tr>
<td></td>
<td>1</td>
<td>2</td>
<td>0</td>
<td>Medium</td>
</tr>
<tr>
<td>12b. How would you rate this aspect of your child’s experience?</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>Low</td>
</tr>
<tr>
<td></td>
<td>0</td>
<td>2</td>
<td>1</td>
<td>NR</td>
</tr>
<tr>
<td>13a. Were you able to say goodbye to your child?</td>
<td>0</td>
<td>13</td>
<td>0</td>
<td>High</td>
</tr>
<tr>
<td></td>
<td>0</td>
<td>2</td>
<td>0</td>
<td>Medium</td>
</tr>
<tr>
<td>13b. How would you rate this aspect of your child’s experience?</td>
<td>4</td>
<td>2</td>
<td>0</td>
<td>Low</td>
</tr>
<tr>
<td></td>
<td>0</td>
<td>2</td>
<td>0</td>
<td>NR</td>
</tr>
<tr>
<td>14a. Did you or your child have the opportunity to clear up any bad</td>
<td>1</td>
<td>6</td>
<td>2</td>
<td>High</td>
</tr>
<tr>
<td>feelings with others?</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>Medium</td>
</tr>
<tr>
<td>14b. How would you rate this aspect of your child’s experience?</td>
<td>4</td>
<td>0</td>
<td>0</td>
<td>Low</td>
</tr>
<tr>
<td></td>
<td>1</td>
<td>1</td>
<td>7</td>
<td>NR</td>
</tr>
<tr>
<td>15a. Did you and or your child have one or more visits from a religious</td>
<td>0</td>
<td>18</td>
<td>0</td>
<td>High</td>
</tr>
<tr>
<td>or spiritual advisor?</td>
<td>0</td>
<td>2</td>
<td>0</td>
<td>Medium</td>
</tr>
<tr>
<td>15b. How would you rate this aspect of your child’s experience?</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>Low</td>
</tr>
<tr>
<td></td>
<td>0</td>
<td>3</td>
<td>0</td>
<td>NR</td>
</tr>
<tr>
<td>16a. Did your child have a spiritual service or ceremony before his/her</td>
<td>3</td>
<td>13</td>
<td>0</td>
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</tr>
<tr>
<td>death?</td>
<td>2</td>
<td>0</td>
<td>0</td>
<td>Medium</td>
</tr>
<tr>
<td>16b. How would you rate this aspect of your child’s experience?</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>Low</td>
</tr>
<tr>
<td></td>
<td>3</td>
<td>1</td>
<td>0</td>
<td>NR</td>
</tr>
<tr>
<td>17a. Did your child receive a mechanical ventilator (respirator) to</td>
<td>2</td>
<td>11</td>
<td>0</td>
<td>High</td>
</tr>
<tr>
<td>breathe for him/her?</td>
<td>0</td>
<td>2</td>
<td>0</td>
<td>Medium</td>
</tr>
<tr>
<td>17b. How would you rate this aspect of your child’s experience?</td>
<td>1</td>
<td>2</td>
<td>0</td>
<td>Low</td>
</tr>
<tr>
<td></td>
<td>0</td>
<td>3</td>
<td>2</td>
<td>NR</td>
</tr>
<tr>
<td>18a. Did your child receive dialysis for his/her urine output?</td>
<td>8</td>
<td>3</td>
<td>0</td>
<td>High</td>
</tr>
<tr>
<td></td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>Medium</td>
</tr>
<tr>
<td>18b. How would you rate this aspect of your child’s experience?</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>Low</td>
</tr>
<tr>
<td></td>
<td>8</td>
<td>0</td>
<td>3</td>
<td>NR</td>
</tr>
</tbody>
</table>
### Table 2. Summary Results of Modified QODD continued

<table>
<thead>
<tr>
<th>19a. Did you make any end of life plans or funeral arrangements for your child prior to his or her death?</th>
<th>No</th>
<th>Yes</th>
<th>DK/NR</th>
<th>Rating</th>
</tr>
</thead>
<tbody>
<tr>
<td>7</td>
<td>2</td>
<td>0</td>
<td>High</td>
<td></td>
</tr>
<tr>
<td>2</td>
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<th>19b. How would you rate this aspect of your child’s experience?</th>
<th>No</th>
<th>Yes</th>
<th>DK/NR</th>
<th>Rating</th>
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<tr>
<th>20a. Were you or your child able to discuss his or her wishes for end of life care with you or with his/her doctor?</th>
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<th>Yes</th>
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<th>20b. How would you rate this aspect of your child’s experience?</th>
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<th>DK/NR</th>
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<table>
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<tr>
<th>21a. Was anyone from your family present at the moment of your child’s death?</th>
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<th>Yes</th>
<th>DK/NR</th>
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<th>21b. How would you rate this aspect of your child’s death?</th>
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<th>Asleep</th>
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<td>0</td>
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<tr>
<th>24. Rate the care your child received from all health care providers (including nurses, caseworkers, doctors and other health care professionals) during the last several days of his or her life while in the ICU.</th>
<th>No</th>
<th>Yes</th>
<th>DK/NR</th>
<th>Rating</th>
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<tr>
<th>25. Rate the care your child received from his or her doctor during the last days of his or her life while in the PICU.</th>
<th>No</th>
<th>Yes</th>
<th>DK/NR</th>
<th>Rating</th>
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Parents varied in their report of how often they or their child experienced the various aspects of care presented in the Modified QODD. Parents also differed in their evaluation of the quality of their experiences. Parents’ ratings of the quality of any aspect of care appear to be influenced by how often an aspect of care was reported to have occurred.

For most items on the QODD, a majority of the participants rated the aspect of care presented in that item as high. However, this rating does appear to be related to how often
they or their child experienced that aspect of care. That is, when examined for how often
an aspect of care occurred a different pattern to the rating of high and low appears. For
example, twelve parents rated highly (7 or greater) the discussion of end-of-life care with
the doctors. Only 2 parents ranked this aspect as low (3 or less). This finding is surprising
given the extent to which families talked in the interviews about how much more
communication or information sharing they needed or desired. Some of this contradiction
might be explained by the extent of the opportunities parents had to discuss end-of-life
care. If parents felt they did not see their doctors often or did not have good relationships
with them, they would have had fewer opportunities to discuss end-of-life care plans. Six
parents reported that they were not able to discuss end-of-life care with their doctor, Two
of these parents rated this aspect as low (2 parents ranked this as being of high quality,
and 2 participants did not provide a ranking). No one who reported that it occurred rated
that experience as being of low quality. These results suggest that parents value end-of-
life discussions.

The item receiving the lowest rating from parents concerned whether their child
was able to be fed or feed him or herself. Ten parents gave this item a low rating and
four parents rated this item as high. Parents of infants may especially have been
concerned about not being able to feed their child or having to stop breast-feeding or
perhaps even never having been able to actually breast feed, but this is not readily
obtained from the Modified QODD. In the interviews only Mary discussed being able to
or wanting to be able to feed her child. There was no target question in the semi-
structured interview designed to capture parents’ feelings about their child’s ability to eat
or be fed.
When examined for whether parents reported that their child was able to be fed at least a good bit of the time, two parents reported yes and both of these parents rated their child being able to eat as low quality. Why these parents felt this way is unexplored with this tool. The Modified QODD does not investigate any aspect of care for more than frequency and parents’ evaluation of the quality of their experience of this aspect of care so it is difficult to say why parents would regard their child’s being able to be fed or to eat as low quality.

Another interesting finding from this tool concerns the item asking about pain and symptom control. For the most part parents reported that their child’s pain and symptoms were controlled most or all of the time and rated this aspect of care quite highly. However, one parent reported that their child’s pain and symptoms were controlled most of the time but rated this aspect of care very low. For this aspect of care, it may be that the side effects (lethargy, stillness, quietness) of the medication used to treat their child’s pain and symptoms may be regarded or remembered by a parent as interfering with their ability to say goodbye to their child. Some parents (though not articulated by them) may even regard these side effects as too suggestive of how their child will look following his or her death.

The Modified QODD was able to discern parents’ rating of the quality of their experience based on the frequency of certain aspects of care occurring. Scores on individual items of the QODD are able to suggest aspects of end-of-life care in need of improvement. However, the QODD scores do not provide specific information on how care might or should be improved. For example, there is one question, #23, on the Modified QODD that asks parents specifically to rank the quality of their child’s death.
When responses to this question are compared to the overall scores on the Modified QODD it is obvious that the tool does provide some indication of parents’ evaluation of their overall experience but asking them to just rate the quality of their child’s dying and death provides a more clear idea that there are aspects of care that parents were or remain unsatisfied with.
Chapter 5
DISCUSSION

Discussion of the findings

Parents are able to remember their experiences in the PICU, recommend changes, and discuss essential aspects to providing good end-of-life care. What they remember about being able to maintain their parenting roles suggests that parents experience role ambiguity when their child requires intensive care. Other researchers have reported that parents are faced with restructuring, perhaps even redefining, their care giving role when their child is in intensive care (Ygge and Arnetz, 2003). Role ambiguity in the PICU is usually caused by uncertainty, lack of information, or loss of perceived roles (Turner, Tomlinson, and Harbaugh, 1990). Parents in this study suggested that more information be provided to parents about what they can do for their children while they are in the PICU and being able to remain involved in hands on care giving would reduce their feelings of uncertainty. Parents want to maintain their parenting role and suggested that the health care team inform and instruct parents on how they can maintain their parenting role while their child is in the PICU. Parents’ stress and anxiety are reduced by being able to remain involved in caring for their child while in the PICU (Curly, 1988).

The recommendations parents made for improving end-of-life care for children and themselves in the PICU focused primarily on providing information to parents. When parents were uncertain of what they were being told they sought out other information sources – often from the internet. Parents needed to understand their child’s condition in...
their own time and at their own level of comprehension. Their personal search for
information might also have been a means to reclaiming some control over such an
uncertain situation. Another explanation could be that the communication taking place in
the PICU may not always be of the information parents need or are able to understand or
attend to given the critical situation they are in.

Researchers have reported how important information and communication is to
patients (Fisher, 1994) and that patients and their families even need to know what is
happening and what to expect (Hupcey and Zimmerman, 2000). The primary need of
parents of critically ill children is to have accurate and comprehensive information
(Farrell and Frost, 1992). The parents in this study reaffirmed these previous findings.
The results of this study revealed that parents consider the most essential aspects of
providing a good death in the PICU are to be able to be present and to have open, honest
and timely communication. The needs of families in the intensive care unit have been
well documented (Farrell and Frost, 1992; Fisher, 1994; Henneman & Cardin, 1992;
Hickey, 1999; Kutner, Steiner, Corbett, Jahnigen, & Barton, 1999; Meyer, E.C., Burns,
J.P., Griffith, J.L., & Truog, R.D., 2002b; Meyers, 2000; Price, Forrester, Murphy, &
Monaghan, 1991; Scott, 1998). This study suggests that essential aspects of care to
providing a good death are not different from what families of patients in the PICU need
in general. However, there is an increased impetus and importance of having these needs
met when they suspect their child is dying.

Parents who have had a child die in the PICU remember if and how they were
able to maintain their parenting role, establish relationships with the health care team,
obtain information, and their child’s discomfort was controlled. These parents had other
comments about the experience of having a child die in the PICU to share. Specifically, parents recalled how different the PICU environment is from anything they had ever experienced before, their experience of grief, their feelings of guilt and regret, how they were making memories of and paying tribute to their child, and their need for follow-up.

**Implications for clinical practice**

These parents’ recollections have clinical implications. Parents coming into the PICU would benefit from a thorough orientation to the intensive care environment. Clinicians working here, especially nurses, could develop some system of telling parents what they can and cannot do in the PICU, how and when they can help with providing hands on care for their child, what to expect if their child’s condition is showing signs of improvement as well as what to expect when their child is not getting better. Some form of clinical follow up from the PICU staff could assist families who have had a child die in reorienting themselves to their daily schedule and redefining themselves as parents who have lost a child. Nurses and nursing have a role in developing policy to ensure parents who have had a child die receive appropriate and timely follow-up.

As the most constant and consistent health care providers at the bedside, nurses coordinate care and communication among themselves and with other members of the health care team to ensure families receive continuity of care. Nurses have a role in mediating and translating information given to families by physicians and in mediating and translating to the rest of the health care team information that the family or patient has shared. Nurses are the primary advocates for patients and their families when advocacy is called for. Of all the members of the health care team, nurses spend the most time with patients and their families. Because of this, they are most able to develop
relationships with their patients’ families. Their unique place at the patient’s bedside
enables nurses to create an environment that maintains family involvement and fosters
family centered care.

For nursing, training in effective communication techniques both during and after
nursing school must be included in the curriculums of schools and health care
institutions. Nurses must improve their own communication skills with patients, families
and colleagues. An important skill to be developed is how to find out from parents and
patients what they are asking for and what they need. Nurse clinicians could develop a
reflective practice where they discuss with other colleagues what these colleagues think
was said and what they think parents or patients heard. Nurses must learn to restate and
clarify what parents and patients hear and understand. They must develop a practice of
returning to give parents and patients the opportunity to ask for more information or
further clarification. As well, nurses must develop skill at anticipating what information
parents and patients might need or want and be able to ask for this information for parents
or assist them in asking for it for themselves.

It is important that clinicians (nurses specifically, but other health team members
as well) explore with parents and discover what it is they want for their child as his or her
death approaches. This will require developing skills at communicating the real
possibilities of a dire outcome for all children who come into the PICU.

When a child does die, clinicians would do well to assist families in creating and
making meaning of their child’s life. Parents could be asked to share a photograph and/or
story about their child to be placed in a PICU memory book Advanced practice nurse
clinicians could assist the PICU staff and the parents in framing the child’s life as special,
meaningful, and valuable through use of positive and reassuring comments, for example:

‘Special children need and get special parents.’

Parents who have lived through having a child die in the PICU have a wealth of knowledge that might ease the experience for other parents of having a child die in the PICU. Parents who want to act as information sources could be contacted and utilized as a system of support for other parents and families. This would serve to inform and support parents facing a new crisis as well as allow parents who have had a child die to make meaning of and contribute to the legacy of their child.

Limitations

This study does have some limitations. Participants self-selected into the study and the sample size is small (14 of the 83 (17%) families experiencing a child’s death in this PICU in 2004 and 2005). Waiting at least 12 months after a child’s death may possibly have introduced some recollection or historical bias. However, research findings suggest that people experiencing the death of a loved one and especially parents experiencing the death of child require at least a year of time to pass before being able to reflect back on the death (Klass, 1993, Klass, 1997). This researcher accepts and acknowledges that survivors need to experience a full year of anniversaries (birthdays, holidays, special family times) without their loved one or child in order to develop some meaning of their loss around these anniversaries.

A further limitation is the exclusion of non-English speaking participants. English is a second language for an increasing number of the population of this PICU and the US health care system. In this study a tenth (eight of 83) of the families experiencing their child’s death in the PICU were identified as Hispanic. Recollections of the experience
and suggestions for improvement may be influenced by cultures and traditions that are different from English-speaking cultures.

This study explored the perspectives of parents of children dying in only one pediatric intensive care unit in a busy, regional university-associated children’s hospital in the southeast US. The experience of having a child die in other pediatric intensive care settings in other regions of the country may be different. The findings reported here may not be easily transferable to other settings.

As well, a relatively new and little tested instrument designed to measure the quality of dying and death in adults was modified to measure parents’ evaluation of the quality of their child’s dying and death experience. Half of the participants did not complete two items in this tool and participants questioned the meaning of several of the remaining items. Despite excluding from analysis the subjects who had missing values for two or more items (resulting in only 14 surveys being examined), the Cronbach’s alpha was .929. Such a high rating suggests that the items in this test may all ask the same thing or that all participants are rating each item the same.

Finally, it is important to note that a leading cause of death in children is traumatic injuries. A serious limitation to these study findings is the absence of participation from parents whose child came to the PICU for treatment of injuries that were the result of trauma. Ten of the 84 children who died in this PICU in 2004 and 2005 were admitted for serious traumatic injuries. Unfortunately, the parents of these children either declined to participate or were unable to be contacted by mail or phone. The experience of having a child die from traumatic injuries may be different from the experience of having a child die from other causes. Traumatic deaths of children may be
unique for parents for many reasons that we do not know about. However, it has been suggested that parents who have suddenly and traumatically had a child die may experience an extended time of grieving despite the passage of time (Hawton, et al 1998), or they may have unresolved feelings about the circumstances surrounding their child’s death (Klass, 1997). These parents may have been able to come to terms with their child’s death and feel little need to discuss the past. However, the literature suggests that parents who lose a child suddenly feel constrained not to talk about their experience and their not participating in this study may reflect this (Dyregrov, 2003). These parents may need some type of intervention earlier in their bereavement to encourage and permit them to reflect on and share their experience.

Areas for future research

Future research should address the development and implementation of several programs. These programs should focus on improving communication skills for all clinicians in the PICU, providing parents who have had a child die in the PICU with grief and bereavement follow-up or referral for follow-up, and allowing parents who want to share their experience to act as PICU parent consultants. Further effort is also needed to investigate how non-English speaking families who have a child die in the PICU remember and evaluate their experience and what recommendations they would make to improve end-of-life care for non-English speaking patients and their families. Investigation is also needed to determine if PICU staff have unmet needs for recognizing and managing their own grief and subsequently developing a program to meet these needs.
Conclusions

This study demonstrated that many parents who have had children die in the PICU are willing to share their experience so that care in this challenging and threatening environment may be improved. These parents acknowledge how difficult it was for them to lose their child. Three important conclusions can be drawn from their stories.

First, parents want more and better communication and information regarding their dying child’s condition. This should not be surprising. For more than twenty years, researchers have reported that parents of children in the hospital, especially parents of children in the PICU rate communication as one of their top needs (Fisher, 1992; Kustner, 1999; Scott, 1998). Even physicians are reported to acknowledge the primary need of parents to be good communication and information sharing (Bartel, Engler, Natale, et al, 2000).

Despite recognizing parents’ need for support and reassurance from the health care team while a child is in intensive care, parents did not always feel this was forthcoming. For health care team members this suggests a need for them to learn and become well practiced in discussing and sharing difficult information early in a child’s PICU admission. As well, members of the PICU team need to develop skills that enable them to explore the parents’ desires for their child if death becomes imminent. Researchers have previously suggested that clinicians need further education in providing communication about and around end-of-life (Curtis, Patrick, Caldwell, and Collier, 2000).
The parents in this study remembered being willing and ready to hear that their child was dying or was likely to die however, these parents reported that communication about the possibility that their child might die was unrealistic or not presented at all. Parents felt that their physicians did not want to talk about the possibility of their child dying because it would be an admission of failure on the part of the health care team. Some of the parents’ reports suggest that physicians might have felt parents were not ready to discuss or plan end-of-life care for their child. This may indeed be the case; physicians’ impression that patients are not ready to talk about end-of-life care has been reported as one of two barriers to discussion of end care. The other barrier to communication about end-of-life care is that physicians often feel that their patient is not yet sick enough to discuss end-of-life care (Curtis, et al 2000).

Directly disregarding parents or causing them to feel unheard interferes with their perception of their parental role and can affect their ability to cope with having a child in the PICU (Katz, 2002). The unfamiliarity of the intensive care setting, the unknown or uncertainty of diagnosis and treatment plans during an acute admission, the loss of control that parents face in this setting would suggest that members of the health care team be especially sensitive in fostering relationships with all parents in the PICU.

Parents who are dealing with having a child in the PICU want to be told as soon as possible, as soon as the doctors know or suspect that their child may indeed die soon. The uncertainty of not knowing interferes with being able to reconcile their impending loss and can affect the trajectory of their grieving. Kirchhoff, Walker, Hutton, et al (2002) described how the uncertainty faced by families of patients in intensive care is compounded by inadequate information. Conclusions from their study recommend
communication that is more effective from the health care team to aid families in understanding and applying the information they are given to their loved one. Parents recognize the difficulty for the health team of being able to pinpoint the time their child will die, but they expressed a desire for clearer communication of when adding or escalating treatment is not going to change the outcome for their child.

Second, how parents discuss and relate the story of having a child die in the PICU is not always reflected in their rating of the quality of their child’s experience using the QODD. Judgment of the quality of end-of-life care is apparently as individual as judgment about quality in general. For parents what is important, like the extent of their grieving or ability to make meaning and pay tribute to their child’s life, has not been considered, measured, or viewed as an aspect of quality of end-of-life care. Parents spoke a great deal about being involved and present in their child’s care but rated their feelings of having any control in the situation very low. It was important for parents to be present but being able to be present alone was insufficient to permit a sense of involvement in their child’s care. To increase parents feeling and sense of control while their child is in the PICU the health team must develop skill in permitting and encouraging parent involvement in all aspects of their child’s care.

Being able to establish good rapport with their children’s caregivers was very important to parents. Having consistent caregivers gave parents a sense of continuity. These parents were able to develop relationships with their child’s health care team and did not have to reintroduce themselves or their child to their child’s PICU caregivers each shift. When communication was not forthcoming, relationships were difficult for parents to establish. Parents felt as if they were being avoided. In listening to parents relate these
experiences the underlying impression was that these parents felt that both they and their child might not have experienced the best care available.

Parents also discussed how they thought or felt their child’s pain and comfort were controlled for and they marked on the QODD that their child’s pain and symptoms were controlled most of the time. This will be good news to clinicians in the PICU who sometimes feel that the pain and symptom control they are able to provide may be inadequate. Yet the fact that one parent rated the quality of this aspect of their child’s experience low points out that individual parents might have different goals for their child’s care at the end-of-life. One might infer that on reflection parents would sacrifice some of their child’s comfort for being able to have their child more alert at the end-of-life. The implication here is that something may be desired and even provided, like good pain control, but it results in an experience that parents’ judge as lower quality. Other researchers have also noted that different aspects of end-of-life care are considered more important depending on the individual and the role they play with the patient (Steinhauser, Christakis, Clipp, et al, 2000). The recommendation is for clinicians to develop some system for discovering what individual parents want for their child and for themselves when their child is dying.

Third, parents experiencing the death of a child in the PICU need a formal intervention or support program that follows them through at least the first year after their child’s death and that is able to continue as individually needed. The parents of this study expressed a great desire, even need, to have care for themselves continued for some time after their child’s death. In earlier research, parents have reported that it takes 3 to 4 years to regain a sense of balance after the death of a child (Klass, 1997).
It may be that parents differ in their understanding or working definition of what support entails, where it might come from, or who might provide it. In the current study parents elaborated on the care they wanted: to be checked on to see how they were faring; to receive information about grief and bereavement for themselves and their children; to be recommended to or have a listing of the grief services available in their area; and, to be able to share their experience. Losing a child is an isolating experience. Being able to share their story can establish or reestablish modes of social support that can reduce parents’ feelings of isolation. Pediatric health care providers are well aware that treating a child involves treating the child’s family. The end-of-life care provided in the PICU when a child dies should not end when his or her family leaves the PICU but should instead reflect the continuum of care diagram in Figure 1 above. Starting with a child’s admission to the PICU discussion with parents should focus on providing and obtaining information that will guide care through diagnosis and intense attempts at curative treatment, continue through to when further escalation of treatment is no longer warranted, and provide individualized care and support for both the child and the child’s family through, at, and beyond the time of death. Providing care on this continuum requires that clinicians in the PICU work to discover what each patient and patient’s family considers essential to providing good care at the end-of-life.

In conclusion, this study sought to examine with parents their memories of having a child die in the PICU and found that parents are willing to not only share these memories but also to offer suggestions for how end-of-life care can be improved in this setting. The findings here suggest two things. First, there is need for improvement in how information about the seriousness of a child’s condition is communicated to parents.
Second, parents who have had a child die need a structured program of follow up to check on their well-being, to educate them about the process of grief, and to assure that they are finding appropriate support in their adjustment to their loss. Future research should address the design, implementation, and effectiveness of a structured follow up program for parents who have had a child die in the PICU.
UNIVERSITY OF WASHINGTON SCHOOL OF MEDICINE

QUALITY OF DYING AND DEATH QUESTIONNAIRE FOR FAMILY MEMBERS – VERSION 3.2A

Please return your completed questionnaire in the enclosed envelope to:

[Return address]

END

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A QUESTIONNAIRE FOR FAMILIES ABOUT
A LOVED ONE’S EXPERIENCES AT THE END OF LIFE

This questionnaire is about experiences that you and your loved one had during his or her stay in the Intensive Care Unit (ICU). We are interested in your experiences because we want to improve the care received by patients and family members.

Some of these questions may be difficult to answer because you may not have had all these experiences. Other questions may be hard to answer because they remind you of a difficult emotional time. Please feel free to skip questions that you find too difficult to answer. This questionnaire will be kept entirely confidential. None of the healthcare providers who provided care to your loved one will see any of your answers.

From your perspective, we would like to know how often your loved one had the experiences described below. Please pick a number from 0 to 5 with “0” indicating “none of the time” and “5” indicating “all of the time”. Then, we would like you to rate this aspect of your loved one’s dying experience on a scale from 0 to 10, where “0” is a “terrible experience”, and “10” is an “almost perfect experience”.

Please make your best effort to choose a number, even if you are not completely certain of the answer. If you cannot pick a number, please circle “Don’t Know” so that we will know that this is a question you cannot answer. We want you to choose a number based on your experience, not what you think your loved one might have answered.

A stamped self-addressed envelope is attached. Please complete this questionnaire and send it back to us as soon as possible. If you have any questions or problems when filling out this questionnaire, please feel free to call us and we’ll do everything we can to assist you. There is also room for your comments at the end of the questionnaire. Once again, thank you for your help.
During the last several days that your loved one was in the ICU:

1a. How often did your loved one appear to have his/her pain under control? (Circle one number)

0  None of the time
1  A little bit of the time
2  Some of the time
3  A good bit of the time
4  Most of the time
5  All of the time
6  Don't know  Go to Question 2a.

b. How would you rate this aspect of your loved one’s dying experience? (Circle one number)

Tentative 0 1 2 3 4 5 6 7 8 9 10 Almost Perfect

2a. How often did your loved one appear to have control over what was going on around him/her? (Circle one number)

0  None of the time
1  A little bit of the time
2  Some of the time
3  A good bit of the time
4  Most of the time
5  All of the time
6  Don't know  Go to Question 3a.

b. How would you rate this aspect of your loved one’s dying experience? (Circle one number)

Tentative 0 1 2 3 4 5 6 7 8 9 10 Almost Perfect
During the last several days that your loved one was in the ICU:

3a. How often was your loved one able to feed her/himself? *(Circle one number)*
   0  None of the time
   1  A little bit of the time
   2  Some of the time
   3  A good bit of the time
   4  Most of the time
   5  All of the time
   6  Don't know  Go to Question 4a.

b. How would you rate this aspect of your loved one's dying experience? *(Circle one number)*

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4a. How often did your loved one appear to breathe comfortably? *(Circle one number)*
   0  None of the time
   1  A little bit of the time
   2  Some of the time
   3  A good bit of the time
   4  Most of the time
   5  All of the time
   6  Don't know  Go to Question 6a.

b. How would you rate this aspect of your loved one's dying experience? *(Circle one number)*

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<th>Almost Perfect</th>
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</table>
During the last several days that your loved one was in the ICU:

5a. How often did your loved one appear to feel at peace with dying? (Circle one number)
   0 None of the time
   1 A little bit of the time
   2 Some of the time
   3 A good bit of the time
   4 Most of the time
   5 All of the time
   6 Don't know >>>>>>>>>> Go to Question 6a.

b. How would you rate this aspect of your loved one's dying experience? (Circle one number)

   Tentive 0 1 2 3 4 5 6 7 8 9 10 Almost Perfect

6a. How often did your loved one appear to be unafraid of dying? (Circle one number)
   0 None of the time
   1 A little bit of the time
   2 Some of the time
   3 A good bit of the time
   4 Most of the time
   5 All of the time
   6 Don't know >>>>>>>>>> Go to Question 7a.

b. How would you rate this aspect of your loved one's dying experience? (Circle one number)

   Tentive 0 1 2 3 4 5 6 7 8 9 10 Almost Perfect
During the last several days that your loved one was in the ICU:

7a. How often did your loved one laugh and smile? (Circle one number)
   0 None of the time
   1 A little bit of the time
   2 Some of the time
   3 A good bit of the time
   4 Most of the time
   5 All of the time
   6 Don't know Go to Question 8a.

b. How would you rate this aspect of your loved one's dying experience?
   (Circle one number)

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8a. How often did your loved one appear to keep his/her dignity and self-respect?
   (Circle one number)
   0 None of the time
   1 A little bit of the time
   2 Some of the time
   3 A good bit of the time
   4 Most of the time
   5 All of the time
   6 Don't know Go to Question 8a.

b. How would you rate this aspect of your loved one's dying experience?
   (Circle one number)

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<th>Terrible</th>
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</table>
During the last several days that your loved one was in the ICU:

9a. How often did your loved one spend time with his/her family or friends? (Circle one number)

   0 None of the time
   1 A little bit of the time
   2 Some of the time
   3 A good bit of the time
   4 Most of the time
   5 All of the time
   6 Don't know >>>>>>>>>>> Go to Question 10a.

b. How would you rate this aspect of your loved one’s dying experience? (Circle one number)

   Tentative 0 1 2 3 4 5 6 7 8 9 10 Almost Perfect

10a. How often did your loved one spend time alone? (Circle one number)

   0 None of the time
   1 A little bit of the time
   2 Some of the time
   3 A good bit of the time
   4 Most of the time
   5 All of the time
   6 Don't know >>>>>>>>>>> Go to Question 11a.

b. How would you rate this aspect of your loved one’s dying experience? (Circle one number)

   Tentative 0 1 2 3 4 5 6 7 8 9 10 Almost Perfect
The following questions are answered with either a "Yes" or "No" based on whether your loved one did certain activities. Please rate the quality of that aspect of the dying experience. Again, we are asking you to focus on your loved one's last several days.

During the last several days that your loved one was in the ICU:

11a. Was your loved one touched or hugged by his/her loved ones? (Circle one number)
   1. Yes
   2. No
   3. Don't know Go to Question 12a.

b. How would you rate this aspect of your loved one's dying experience?
   (Circle one number)

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12a. Were all of your loved one's health care costs taken care of? (Circle one number)
   1. Yes
   2. No
   3. Don't know Go to Question 13a.

b. How would you rate this aspect of your loved one's dying experience?
   (Circle one number)

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REMEMBER: IF YOU HAVE ANY QUESTIONS, PLEASE CALL.
During the last several days that your loved one was in the ICU:

13a. Did your loved one say goodbye to loved one? (Circle one number)
   1 Yes
   2 No
   3 Don't know Go to Question 14a.

b. How would you rate this aspect of your loved one's dying experience? (Circle one number)

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14a. Did your loved one clear up any bad feelings with others? (Circle one number)
   1 Yes
   2 No
   3 Don't know Go to Question 15a.

b. How would you rate this aspect of your loved one's dying experience? (Circle one number)

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15a. Did your loved one have one or more visits from a religious or spiritual advisor? (Circle one number)
   1 Yes
   2 No
   3 Don't know Go to Question 16a.

b. How would you rate this aspect of your loved one's dying experience? (Circle one number)

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During the last several days that your loved one was in the ICU:

16a. Did your loved one have a spiritual service or ceremony before his/her death?  
(Circle one number)  
1 Yes  
2 No  
3 Don't know Go to Question 17a.

b. How would you rate this aspect of your loved one's dying experience?  
(Circle one number)

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17a. Did your loved one receive a mechanical ventilator (respirator) to breathe for him/her?  
(Circle one number)  
1 Yes  
2 No  
3 Don't know Go to Question 18a.

b. How would you rate this aspect of your loved one's dying experience?  
(Circle one number)

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18a. Did your loved one receive dialysis for his/her kidneys?  
(Circle one number)  
1 Yes  
2 No  
3 Don't know Go to Question 19a.

b. How would you rate this aspect of your loved one's dying experience?  
(Circle one number)

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Please answer either “Yes” or “No” if your loved one ever experienced the following. Then, rate the quality of this aspect of your loved one’s dying experience.

19a. Did your loved one have his or her funeral arrangements in order prior to death?  
*(Circle one number)*

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b. How would you rate this aspect of your loved one’s dying experience?  
*(Circle one number)*

19b. Did your loved one have his or her funeral arrangements in order prior to death?  
*(Circle one number)*

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20a. Did your loved one discuss his or her wishes for end of life care with his/her doctor -- for example, resuscitation or intensive care?  
*(Circle one number)*

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b. How would you rate this aspect of your loved one’s dying experience?  
*(Circle one number)*
21a. Was anyone present at the moment of your loved one's death? *(Circle one number)*

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b. How would you rate this aspect of your loved one's death? *(Circle one number)*

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22a. In the moment before your loved one's death, was he/she:

1. Awake
2. Asleep
3. In a coma or unconscious
4. Don't know >>>>>>>>>> Go to Question 23.

b. How would you rate this aspect of your loved one's death? *(Circle one number)*

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23. Overall, how would you rate the quality of your loved one's dying? *(Circle one number)*

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24. Rate the care your loved one received from all doctors and other health care providers (including nurses, caseworkers, and other health care professionals) during the last several days of his or her life while in the ICU. *(Circle the number)*

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<tr>
<th>Worst Healthcare Possible</th>
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<th>Best Healthcare Possible</th>
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</table>

25. Rate the care your loved one received from his or her doctor during the last several days of his or her life while in the ICU. *(Circle the number)*

<table>
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<tr>
<th>Worst Healthcare Possible</th>
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<th>Best Healthcare Possible</th>
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**REMEMBER: IF YOU HAVE ANY QUESTIONS, PLEASE CALL.**
ABOUT YOU

In this section, we would like to ask a few questions about you and about your loved one.

1. When were you born? (Please write the year)
   19

2. When was your loved one born? (Please write the year)
   19

3. What is your gender? (Circle one number)
   1 Male
   2 Female

4. What is your loved one’s gender? (Circle one number)
   1 Male
   2 Female

5. Approximately how many days was your loved one in the hospital? (Please write the number of days)
   ___________ days

6. Approximately how many days was your loved one in the intensive care unit (ICU)? (Please write the number of days)
   ___________ days

7. What is your ethnicity? (Circle one number)
   1 Hispanic
   2 Non-Hispanic
8. What is your race? (Circle all that apply)
   1 White
   2 Black / African American
   3 Asian
   4 Pacific Islander
   5 Native American or Alaskan Native
   6 Other (please specify) __________________________

9. What is the highest level of schooling you have completed? (Circle one number)
   1 8th grade or less
   2 Some high school
   3 High school diploma or GED
   4 Some college or trade school
   5 4-year college degree (e.g. BA, BS)
   6 Graduate or professional school

10. How are you related to your loved one? (Circle one number)
    1 I am his/her spouse or partner
    2 I am his/her child
    3 I am his/her sibling
    4 I am his/her parent
    5 I am another relative
    6 I am his/her friend
    7 Other (please specify) __________________________

11. Did you live with your loved one? (Circle one number)
    1 Yes
    2 No
12. How long have you known your loved one? (Please fill in)
   _______ number of years  OR  _______ number of months

13. Today's date is: (Please fill in today's date)
   __________/_________/_________ Year

14. We would like to get feedback from you on how burdensome it was to complete this questionnaire. This information will help guide us in future research.
   Overall, how much of a burden on you was this questionnaire? (Circle one number)

<table>
<thead>
<tr>
<th>No burden at all</th>
<th>Moderate burden</th>
<th>Great burden</th>
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Thank you for taking the time to complete this survey. If you have any comments, please feel free to add them to the margins of the survey or to the space below, or call to talk with study staff. Thank you again for your help.
Appendix B
Modified Quality of Dying and Death Questionnaire
Adapted with permission

A QUESTIONNAIRE FOR FAMILIES ABOUT THEIR CHILD’S EXPERIENCES AT THE END-OF-LIFE IN THE PICU
Adapted (with permission) from the University of Washington School of Medicine Quality of Dying and Death Questionnaire for Family Members – Version 3.2A

This questionnaire is about experiences that you and your child had during his or her stay in the Pediatric Intensive Care Unit (PICU). We are interested in your experiences because we want to improve the care received by children, their parents and family members in the PICU.

Some of these questions may be difficult to answer because you may not have had all these experiences or because they remind you of a difficult emotional time. Please feel free to skip questions that you find too difficult to answer.

This questionnaire will be kept entirely confidential. None of the healthcare providers who provided care to your child will see any of your answers.

From your perspective, we would like to know how often your child had the experiences described below. Please pick a number from 0 to 5 with “0” indicating “none of the time” and “5” indicating “all of the time”.

Then, we would like you to rate this aspect of your child’s dying experience on a scale from 0 to 10, where “0” is a “terrible experience”, and “10” is an “almost perfect experience”.

Please make your best effort to choose a number, even if you are not completely certain of the answer. If you cannot pick a number, please circle “Don’t Know” so that we will know that this is a question you cannot answer. We want you to choose a number based on your experience, not what you think your child might have answered.

If you have any questions or problems when filling out this questionnaire, please share them with the researcher.

There is also room for your comments at the end of the questionnaire. Once again, thank you for your help.
During the last several days that your child was in the PICU:

1a. How often did your child appear to have his/her pain under control? (Circle one number)

   0 None of the time
   1 A little bit of the time
   2 Some of the time
   3 A good bit of the time
   4 Most of the time
   5 All of the time
   6 Don’t know >>>>>>>> Go to Question 2a.

b. How would you rate this aspect of your child’s experience in the PICU? (Circle one number)

   Terrible 0 1 2 3 4 5 6 7 8 9 10 Almost Perfect

2a. How often did you feel you had control over what was going on with your child in the pediatric intensive care unit? (Circle one number)

   0 None of the time
   1 A little bit of the time
   2 Some of the time
   3 A good bit of the time
   4 Most of the time
   5 All of the time
   6 Don’t know >>>>>>>> Go to Question 3a.

b. How would you rate this aspect of your child’s experience? (Circle one number)

   Terrible 0 1 2 3 4 5 6 7 8 9 10 Almost Perfect
During the last several days that your child was in the ICU:

3a. How often was your child able to be fed or feed her/himself? (Circle one number)

0 None of the time
1 A little bit of the time
2 Some of the time
3 A good bit of the time
4 Most of the time
5 All of the time
6 Don’t know >>>>>>>>>>>> Go to Question 4a.

b. How would you rate this aspect of your child’s experience? (Circle one number)
Terrible 0 1 2 3 4 5 6 7 8 9 10 Almost Perfect

4a. How often did your child appear to breathe comfortably? (Circle one number)

0 None of the time
1 A little bit of the time
2 Some of the time
3 A good bit of the time
4 Most of the time
5 All of the time
6 Don’t know >>>>>>>>>>>> Go to Question 5a.

b. How would you rate this aspect of your child’s experience? (Circle one number)
Terrible 0 1 2 3 4 5 6 7 8 9 10 Almost Perfect
During the last several days that your child was in the ICU:

5a. How often did your child appear to feel at peace?  
   \textit{(Circle one number)}
   
   0 None of the time
   1 A little bit of the time
   2 Some of the time
   3 A good bit of the time
   4 Most of the time
   5 All of the time
   6 Don’t know \textit{Go to Question 6a}

b. How would you rate this aspect of your child’s experience?  
   \textit{(Circle one number)}
   
   Terrible 0 1 2 3 4 5 6 7 8 9 10 Almost Perfect

6a. How often did your child appear to be afraid?  \textit{(Circle one number)}

   0 None of the time
   1 A little bit of the time
   2 Some of the time
   3 A good bit of the time
   4 Most of the time
   5 All of the time
   6 Don’t know \textit{Go to Question 7a.}

b. How would you rate this aspect of your child’s experience?  
   \textit{(Circle one number)}
   
   Terrible 0 1 2 3 4 5 6 7 8 9 10 Almost Perfect
During the last several days that your child was in the ICU:

7a. How often was your child able to laugh and smile? (Circle one number)

0 None of the time
1 A little bit of the time
2 Some of the time
3 A good bit of the time
4 Most of the time
5 All of the time
6 Don’t know >>>>>>>>> Go to Question 8a.

b. How would you rate this aspect of your child’s experience?
(Circle one number)

Terrible 0 1 2 3 4 5 6 7 8 9 10 Almost Perfect

8a. How often did your child appear to keep his/her dignity and self-respect?
(Circle one number)

0 None of the time
1 A little bit of the time
2 Some of the time
3 A good bit of the time
4 Most of the time
5 All of the time
6 Don’t know >>>>>>>>> Go to Question 9a.

b. How would you rate this aspect of your child’s experience?
(Circle one number)

Terrible 0 1 2 3 4 5 6 7 8 9 10 Almost Perfect
During the last several days that your child was in the ICU:

9a. How often was your child able to spend time with family members or friends? (Circle one number)

0 None of the time
1 A little bit of the time
2 Some of the time
3 A good bit of the time
4 Most of the time
5 All of the time
6 Don’t know >>>>>>>> Go to Question 10a.

b. How would you rate this aspect of your child’s experience? (Circle one number)

Terrible 0 1 2 3 4 5 6 7 8 9 10 Almost Perfect

10a. How often did your child spend time alone? (Circle one number)

0 None of the time
1 A little bit of the time
2 Some of the time
3 A good bit of the time
4 Most of the time
5 All of the time
6 Don’t know >>>>>>>> Go to Question 11a.

b. How would you rate this aspect of your child’s experience? (Circle one number)

Terrible 0 1 2 3 4 5 6 7 8 9 10 Almost Perfect
The following questions are answered with either a “Yes” or “No” based on whether your child did certain activities. Please rate the quality of that aspect of the dying experience. Again, we are asking you to focus on your child’s last several days.

**During the last several days that your child was in the ICU:**

11a. **Was your child able to be touched or hugged by his/her friends, family, others?**

*(Circle one number)*

1 Yes

2 No

3 Don’t know >>>>>>>> Go to Question 12a.

b. **How would you rate this aspect of your child’s experience?**

 *(Circle one number)*

Terrible 0 1 2 3 4 5 6 7 8 9 10 Almost Perfect

12a. **Were all of your child’s health care costs taken care of?** *(Circle one number)*

1 Yes

2 No

3 Don’t know >>>>>>>> Go to Question 13a.

b. **How would you rate this aspect of your child’s experience?**

 *(Circle one number)*

Terrible 0 1 2 3 4 5 6 7 8 9 10 Almost Perfect

REMEMBER: IF YOU HAVE ANY QUESTIONS, PLEASE ASK.
During the moments or days that your child was in the ICU:

13a. Were you able to say goodbye to your child? (Circle one number)

1 Yes
2 No
3 Don’t know >>>>>>> Go to Question 14a.

b. How would you rate this aspect of your child’s experience? (Circle one number)

Terrible 0 1 2 3 4 5 6 7 8 9 10 Almost Perfect

14a. Did you or your child have the opportunity to clear up any bad feelings with others? (Circle one number)

1 Yes
2 No
3 Don’t know >>>>>>> Go to Question 15a.

b. How would you rate this aspect of your child’s experience? (Circle one number)

Terrible 0 1 2 3 4 5 6 7 8 9 10 Almost Perfect

15a. Did you and or your child have one or more visits from a religious or spiritual advisor?
(Circle one number)

1 Yes
2 No
3 Don’t know >>>>>>> Go to Question 16a.

b. How would you rate this aspect of your child’s experience? (Circle one number)

Terrible 0 1 2 3 4 5 6 7 8 9 10 Almost Perfect
During the last several days that your child was in the ICU:

16a. Did your child have a spiritual service or ceremony before his/her death? (Circle one number)

1 Yes
2 No
3 Don’t know >>>>>>>> Go to Question 17a.

b. How would you rate this aspect of your child’s experience? (Circle one number)

Terrible 0 1 2 3 4 5 6 7 8 9 10 Almost Perfect

17a. Did your child receive a mechanical ventilator (respirator) to breathe for him/her? (Circle one number)

1 Yes
2 No
3 Don’t know >>>>>>>> Go to Question 18a.

b. How would you rate this aspect of your child’s experience? (Circle one number)

Terrible 0 1 2 3 4 5 6 7 8 9 10 Almost Perfect

18a. Did your child receive dialysis for his/her urine output? (Circle one number)

1 Yes
2 No
3 Don’t know >>>>>>>> Go to Question 19a.

b. How would you rate this aspect of your child’s experience? (Circle one number)

Terrible 0 1 2 3 4 5 6 7 8 9 10 Almost Perfect
Please answer either “Yes” or “No” if your child ever experienced the following. Then, rate the quality of this aspect of your child’s dying experience.

19a. Did you make any end-of-life plans or funeral arrangements for your child prior to his or her death? (Circle one number)

1 Yes
2 No
3 Don’t know >>>>>>>>> Go to Question 20a.

b. How would you rate this aspect of your child’s experience? (Circle one number)

Terrible 0 1 2 3 4 5 6 7 8 9 10 Almost Perfect

20a. Were you or your child able to discuss his or her wishes for end-of-life care with you or with his/her doctor -- for example, CPR or treatment choices? (Circle one number)

1 Yes
2 No
3 Don’t know >>>>>>>>> Go to Question 21a.

b. How would you rate this aspect of your child’s experience? (Circle one number)

Terrible 0 1 2 3 4 5 6 7 8 9 10 Almost Perfect

21a. Was anyone from your family present at the moment of your child’s death? (Circle one number)

1 Yes
2 No
3 Don’t know >>>>>>>>> Go to Question 22a.

b. How would you rate this aspect of your child’s death? (Circle one number)

Terrible 0 1 2 3 4 5 6 7 8 9 10 Almost Perfect
22a. In the moments before your child’s death, was he/she: (Circle one number)

1 Awake
2 Asleep
3 In a coma or unconscious
4 Don’t know >>>>>>> Go to Question 23.

b. How would you rate this aspect of your child’s death? (Circle one number)
Terrible 0 1 2 3 4 5 6 7 8 9 10 Almost Perfect

23. Overall, how would you rate the quality of your child’s dying? (Circle one number)
Terrible 0 1 2 3 4 5 6 7 8 9 10 Almost Perfect

24. Rate the care your child received from all health care providers (including nurses, caseworkers, doctors and other health care professionals) during the last several days of his or her life while in the ICU. (Circle the number)

Worst Healthcare 0 1 2 3 4 5 6 7 8 9 10 Healthcare Possible
Best Possible

25. Rate the care your child received from his or her doctor during the last days of his or her life while in the PICU. (Circle the number)

Worst Healthcare 0 1 2 3 4 5 6 7 8 9 10 Healthcare Possible
Best Possible

REMEMBER: IF YOU HAVE ANY QUESTIONS, PLEASE ASK.
ABOUT YOU
In this section, we would like to ask a few questions about you and about your child.

1. When were you born? (Please write the year)
   19 _____ _____

2. When was your child born? (Please write the year)
   _____ _____

3. What is your gender? (Circle one number)
   1 Male
   2 Female

4. What is your child’s gender? (Circle one number)
   1 Male
   2 Female

5. Approximately how many days was your child in the hospital? 
(Please write the number of days)
   ____________ days

6. Approximately how many days was your child in the intensive care unit (ICU)? (Please write the number of days)
   ____________ days

7. What is your ethnicity? (Circle one number)
   1 Hispanic
   2 White/Caucasian
   3 Black/African-American
   4 Other (please write in)
   ____________________________________________

8. What is your race? (Circle all that apply)
   1 White
   2 Black / African American
   3 Asian
   4 Pacific Islander
   5 Native American or Alaskan Native
   6 Other (please specify) ______________________________
9. What is the highest level of schooling you have completed? (Circle one number)
   1 8th grade or less
   2 Some high school
   3 High school diploma or GED
   4 Some college or trade school
   5 4-year college degree (e.g. BA, BS)
   6 Graduate or professional school

10. How are you related to your child? (Circle one number)
    1 I am his/her mother
    2 I am his/her father
    3 I am his/her grandparent
    4 I am his/her foster parent
    5 I am another relative
    6 Other (please specify) ______________________________

11. Did your child live with you? (Circle one number)
    1 Yes
    2 No

12. We would like to get feedback from you on how burdensome it was to complete this questionnaire. This information will help guide us in future research. Overall, how much of a burden on you was this questionnaire? (Circle one number)

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Thank you for taking the time to complete this survey. If you have any comments, please feel free to add them to the margins of the survey or to the space below, or talk with study staff. Thank you again for your help.
Appendix C

Proposed Interview Guide
Guide to semi-structured interview with parents whose children have died in the PICU

I am very interested in improving the experience of dying and death for children and their families. While fewer children die today than in times past those that do are frequently in the pediatric intensive care setting when they die. The purpose of this study is to gather information about how to improve dying and death for children in the pediatric intensive care unit. Health care providers have ideas about how care might be changed to improve dying and death but the parents who have had a child die in the PICU are the best source of information for how this experience might be made better. The memories you have of your child’s dying and death in the PICU are unique and valuable. The information you share will help shape the future of end-of-life care for children and their families in the PICU.

1) Tell me the story of how your child died in the PICU.

2) What did you find helpful at this time?

3) What actions or behaviors helped you to maintain your family roles in the PICU?

4) What helped or interfered with you or your child being able to develop relationships with care providers?

5) What do you remember about the information exchange between you and the health care team?

6) In your remembering how well were your child’s pain and symptoms controlled?

7) What systems of support do you remember being offered by the health care team? Which of these supports were valuable to you? What other support would you have appreciated?

8) What other things would you like to have had happen that might have made this a better dying and death for your child?

9) What things might have been done to make the memories of having a child die in the PICU better for you?

10) Is there anything else you would like to say about your experience of having your child die in the Pediatric Intensive Care Unit?
Appendix D
Study Letter to Parents

LETTER OF INVITATION

Dear Parent (name):

I am writing to invite you to participate in an interview about end-of-life care for children in the pediatric intensive care unit. I am very interested in improving the experience of dying and death for children and their families. While fewer children die today than in the past those that do are often in the pediatric intensive care setting when they die. The purpose of this study is to gather information about how to improve this experience for children and their families in the pediatric intensive care unit. Health care providers have ideas about how care might be changed to improve dying and death but the parents who have had a child die in the PICU are the best source of information for how this experience might be made better. The memories you have of your child’s experience in the PICU are unique and valuable. The information you share will help shape the future of end-of-life care for children and their families in the PICU. This study is the research component of my doctoral studies.

During this study parents will be asked what they remember about having a child die in the PICU and what recommendations they would make that might improve this experience for others. The interview will take 1-2 hours and will be audio taped and transcribed. Your responses will be confidential and the audiotapes reviewed only by the research team. You may also receive a follow-up phone call to review the content of the interviews for clarification, to make sure the interpretations made by the study team are the real meaning you intended.

I look forward to your participation. Please indicate your interest in participating in this study by completing the enclosed contact information/willingness to participate form, enclose the form in the envelope provided, and mail it at your earliest convenience. If I do not receive your response by [DATE, two-three weeks after initial mailing], my research assistant (Nathalie Cozon RN BSN) will attempt contact you by phone to assure you received this information and to determine your availability and willingness to participate. If you have any questions, please contact me at (919 929 2476).

Thank you for your consideration of this important project.

Sincerely,

Diane Yorke RN MSN MBA
Doctoral Candidate

Enc: Study Frequently Asked Questions information sheet
   Contact information - willingness to participate form
   Stamped addressed return envelope
Appendix E

**Frequently Asked Questions**

*Parents’ Reflections on the Quality of the Dying and Death of Their Children in the Pediatric Intensive Care Unit: What is a Good Death?*

**What is this project about?**
This project is a study of end-of-life care in the Pediatric Intensive Care Unit (PICU). The purpose of the study is to gain a better understanding of the nature of end-of-life care for children and their families in the PICU, including the range of services and the quality of care provided. This is a qualitative study to examine the perspectives of parents of children who died in the PICU. The results of the qualitative investigation will inform health care providers in the PICU of how end-of-life care in the PICU may be improved. Findings from the study will contribute to the development of evidence-based practices for end-of-life care in the PICU.

**Who is doing this project?**
This project is the research component of the principal investigator’s PhD dissertation. The principal investigator, Diane Yorke, RN MSN MBA, is a staff nurse in the PICU where your child died.

**Who is funding this project?**
Application has been made to the nursing honor society (Sigma Theta Tau), the American Association of Critical Care Nurses, the Society of Critical Care Medicine.

**Where is the study being conducted?**
The study site for this study is the PICU of the University of North Carolina Children’s Hospital. Interviews will take place in a setting convenient to study participants.

**Who will participate?**
Twenty parents of 20 children who died in the PICU will be interviewed and complete a questionnaire.

All children who died in this PICU from November 2003 until November or 2005 will be identified. Their parents’ contact information will be obtained from these children’s medical records. The medical records of the children whose parents agree to participate will be further examined for information about their last days in the PICU.

**Do I have to participate and will anyone know whether or not I participate?**
Your participation in this study is voluntary. No one will be informed if you decide to participate or not to participate.
**How will you use the information?**

Only the study investigators will read the interview transcripts. The investigators will read the transcripts to identify themes and these themes will be summarized across the interviews. This information will contribute to the improvement of the nature and quality of care in the PICU.

**Who will know what I say?**

Only the members of the study investigative team will read the interview transcripts. We will not report anything that will reveal an individual’s identity.

**Can I get a copy of the results?**

We would be happy to inform you when results from the study are published. You can contact Diane Yorke, RN at UNC Children’s Hospital (919 929 2476) for more information about the study results and publications.
Appendix F

Parent Return Contact Information Form

Parents’ Reflections on the Quality of Dying and Death for Their Children in the PICU

Please indicate your interest in participating in this study by checking ONE of the 2 boxes below. Please be sure to write your name and contact information if you agree to participate in this study. Place this form in the stamped addressed envelope provided and return it in the mail. You will be contacted by phone within one month to arrange an interview time that is convenient for you.

☐ I am willing and available to participate in this study of what parents remember about their child’s end-of-life experiences in the Pediatric Intensive Care Unit.

PRINT NAME

PRINT ADDRESS

PHONE NUMBER(S)

BEST TIME TO CALL TO ARRANGE APPOINTMENT

☐ I do not wish to participate in this study.

PRINT NAME
Dear Parents and Grandparents of the PICU Parent Study:

Thank you for letting me interview you regarding your experiences with having a child die in the Pediatric Intensive Care Unit. The views and experiences you described are tremendously helpful to my research and the ultimate goal of improving end-of-life care in the PICU. I very much appreciate your sharing your time and thoughts. I may be calling you to review the summary of my results in a few weeks. I may also send you a copy of this summary to review. Your comments and feedback will assure me that I have captured the correct information about your experience.

If you have any question please contact me at (919) 929 2476.

Again, thank you for your help with this study.

Sincerely,

Diane Yorke, RN MSN MBA
Doctoral Candidate
### Appendix H

**Subjects’ Individual Responses to Modified QODD**

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