

DECISIONS TO FORGO LIFE-SUSTAINING MEDICAL
TREATMENT IN A CANADIAN PAEDIATRIC CRITICAL
CARE UNIT (PCCU): MATERNAL PERCEPTION OF
SUBSEQUENT FAMILY ADJUSTMENT

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ELIZABETH ANNE VOTTA



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IN A CANADIAN PÆDIATRIC CRITICAL CARE UNIT (PCCU):
MATERNAL PERCEPTION OF SUBSEQUENT FAMILY ADJUSTMENT**

BY

©ELIZABETH ANNE VOTTA

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requirements for the degree of
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ABSTRACT

Maternal perception of family adjustment following three types of decisions regarding a child's life-sustaining medical treatment was evaluated. Participants were mothers whose child died following a discussion to forgo life-support ($n = 18$); child died, but a discussion to forgo life-support did not occur ($n = 6$); and child survived despite the fact that a member of the medical staff felt a discussion to forgo life-support should have occurred ($n = 16$). A fourth group of mothers of chronically ill children ($n = 106$) visiting the hospital's out-patient clinics was included as a comparison group for a family functioning measure. Groups differed significantly in family functioning; Group 1 families were marginally less cohesive and adaptable than families in Groups 2, 3 and 4. Mothers did not differ in their perception of the hospital decision-making experience, nor stress arising from the Pædiatric Critical Care Unit (PCCU). With respect to maternal psychological symptom status, mothers in Group 2 exhibited a more intense symptom pattern than did mothers in Group 3, who in turn exhibited a more intense pattern than mothers in Group 1. Maternal ratings of siblings behaviours differed significantly; siblings in Group 1 were rated as exhibiting fewer internalizing and externalizing behaviour problems than siblings in Groups 2 and 3. Although not correlated with maternal psychological symptomatology, family functioning correlated with the number of positive mother-child interactions. The intensity of maternal psychological symptom status correlated with maternal perceptions of total PCCU stress and behaviour problems exhibited by siblings. Implications of the PCCU experience and decisions to forgo life-support on family adjustment are discussed.

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**Decisions to Forgo Life-Sustaining Medical Treatment
in a Canadian Pædiatric Critical Care Unit (PCCU):
Maternal Perception of Subsequent Family Adjustment**

Within the field of pædiatric critical care medicine, the impact of changing medical technology has extended to both the family and health care domains. On one hand, changes may be credited with increased longevity in chronically ill children, thus necessitating familial adjustment to the illness. On the other, changes may be seen as means of prolonging life long enough to allow family and health care professionals time to decide whether life should be maintained in its present state, or whether all life-supporting means should be ceased. Families deciding to continue life-support must adapt to stressors associated with pædiatric intensive care units (Riddle, Hennessey, Eberly, Carter, & Miles, 1989), while other families must accept their decision to discontinue sustaining their child's life-support.

From either perspective, the relationship of technology to the death of a child precipitates a potential crisis situation. Death due to the forgoing of treatment may shatter the family's normal coping skills (Johnson & Mattson, 1992) and/or impair its long-term functioning. Decades ago, parents did not contemplate the decision to forgo life-support, as medical technology was not yet in a position to prolong life when faced with most life-threatening ailments. Therefore, little research has been conducted regarding the impact on family members of discussions and eventual decisions to forgo a child's life-support. In this study, maternal perception of family adjustment following decisions between parents

and physicians to forgo their critically ill child's life-support was examined.

Family Adjustment to Chronic Illness

Recent medical technology has greatly improved the survival rate and quality of life for critically ill children in comparison to children with the same illnesses decades earlier (Hamlett, Pellegrini, & Katz, 1992). Increases in survival rate have raised the ethical issue of infant euthanasia, necessitated greater understanding of the psychological development of chronically ill children, and demanded adjustments in the dynamics of the families of chronically ill children.

Families in which a childhood chronic illness is present are characterized by a broad range of family functioning (Kazak, 1989). Chronic illness necessitates adaptations in the coping responses of both the child and family, and has many implications for all family members. These may include employment options of parents, creation of more in-home work, and limitations in job mobility (Perrin & MacLean, 1988). Researchers have found familial characteristics influence the child's and family's appraisal of stressors and their ensuing choice of adaptive responding (Hamlett et al., 1992). The family is also said to either buffer or intensify the disruptive effects of the stressors associated with a chronic illness (Hamlett et al., 1992).

Bereavement and Ensuing Family Functioning

Death, grief, and bereavement remain inevitable life experiences with which surviving family members of chronically ill children must endure. Grieving refers to the process of experiencing and expressing the emotional impact of a loss. This process

progresses from extreme grief to recovery (Church, 1981 as cited in Valeriotte & Fine, 1987; Valeriotte & Fine, 1987; Hardt, 1978) and may include feelings of shock, numbness, confusion, anxiety, rage, pain, sadness and depression (Futterman & Hoffman, 1983).

Bereavement processes are further varied given that modes and length of grief expression are influenced by one's culture, religion, customs, age of deceased, and circumstances surrounding the death (Hardt, 1978; Church, 1981 as cited in Valeriotte & Fine, 1987; Valeriotte & Fine, 1987). Sudden-death griever, for example, are more likely to experience guilt, anger, and prolonged physical repercussions; anticipated-death griever are more apt to experience feelings of isolation, which prolong grief (Sanders, 1982).

As parental anguish following the death of a child has been identified as the most intense form of grief (Crenshaw, 1991; Valeriotte & Fine, 1987), the impact of a child's death on the family unit may be so significant as to put the family at risk of dysfunction. Family structure prior to the child's death, family's ability to mourn, and age of child at his/her death will affect family adjustment to the loss (Valeriotte & Fine, 1978).

Some researchers have found parental participation in the care of one's dying child can help families adjust to the child's death (Nolfie, 1977); others have found factors such as death by suicide, sudden death (e.g., SIDS), accidental death, miscarriage, stillbirth, and neonatal death, may complicate parents' bereavement (Valeriotte & Fine, 1978).

Comparisons between maternal and paternal bereavement styles have indicated mothers grieve more than fathers, have greater difficulty coping on significant holidays, are more apt to take up new interests, and report feeling distant from their spouse; fathers, who are

often given the task of making funeral arrangements, identifying the body, and notifying family members, are said to have greater difficulties expressing their grief (Page-Lieberman & Hughes, 1990; Cook, 1981 as cited in Valeriotte & Fine, 1987).

In considering the impact of a child's death on the family, one must also recognize effects on surviving siblings. Siblings' perceptions of death are dependent upon their developmental stage, environment, life experiences, and parents' attitudes (Glickin, 1978). Developmental theorists have proposed preschoolers tend to have difficulties grasping what another's death entails (Costa & Holliday, 1992). Bereavement in preschoolers has been characterized by many of the following reactions: indifference, shock, denial, anger, withdrawal, fear, and guilt (Costa & Holliday, 1992; Coppolillo, 1991). Preschoolers also tend to misconstrue death's irreversibility, its cause, and parents' grief (Costa & Holliday, 1992). To aid them in their grief, preschoolers must have death explained to them in simple terms, assured they were not the cause, and reassured the same will not happen to themselves or their parents (Costa & Holliday, 1992; Coppolillo, 1991). Older siblings may also experience distorted concepts of illness and death; disturbed attitudes toward doctors, hospitals and religion; death phobias; comparisons, identification and misidentification with deceased sibling; and disturbances in cognitive functioning (Cain, Fast, & Erickson, 1977). Grief and guilt reactions may be manifested as nightmares, sleeplessness, enuresis, headaches, appetite loss, dazed states, and anti-social acting out (Krell & Rabkin, 1979).

Researchers studying adolescent bereavement have concluded family recognition and response to surviving siblings' needs play important roles in determining sibling adjustment to the death experience and subsequent family interactions (Martinson & Campos, 1991). In the surviving sibling, links have been demonstrated between sibling death and depression (Blinder, 1972), anxiety and fear of failure (Cairns, Clark, Smith, & Lansky, 1979), sleep disturbances, somatic complaints, and social and affective changes (Walker, 1989). Difficulty communicating about death is also thought to disrupt adjustment as it forces siblings to face their fears alone (McNeil, 1986; Thompson, 1989).

In addition to guilt and anger, long-term problems may arise for the family as a result of other repercussions. Unresolved grief is grief which the bereaved has been unable to express (Valeriote & Fine, 1978). Unexpressed grief can arrest an individual family member or the entire family unit at any point in the mourning process, and may be manifested as somatic pain, depression, anxiety, withdrawal, and/or suicidal thoughts (Valeriote & Fine, 1978).

Parents consumed by their own grief, may engage in protective manoeuvres to ease their anguish. The "replacement child", a protective manoeuvre resulting when parents attempt to restore the missing child in order to deny the harsh reality of their child's death (Krell & Rabkin, 1979; Valeriote & Fine, 1978). may be a child born following the death, or a surviving sibling. As the surviving child becomes the focus in parents' adaptive measures to create a new family balance, surviving siblings may experience changes in parents and the ways parents relate to them (Krell & Rabkin, 1979;

Valeriotte & Fine, 1978). Parents may accord the surviving child a special status characterized by over-protectiveness (Krell & Rabkin, 1979), or be unable to talk about or explain the death to the sibling (Valeriotte & Fine, 1978). In some families, parents may suppress the facts surrounding the child's death, such that the surviving child may know little about his/her deceased sibling (Krell & Rabkin, 1979). Some parents may also withdraw or lessen their emotional ties with the child, as if in preparation for the potentiality of another loss (Krell & Rabkin, 1979).

Family Adaptation to Impending Death

When faced with the loss of a child due to illness, parents have time to spend both with the child and the notion of impending death. Parents in this position pass through what some researchers refer to as the confrontational stage, which includes three tasks (McCollum, 1983). First, parents must assimilate the reality of their child's illness. When confronted with the possible death of their child, parents may appraise such defenses as denial. In denying the possibility of death, parents may hinder their ability to gather information constructively.

Second, parents must master the anticipatory grief reaction. In doing so, parents may experience a combination of emotions: self-accusatory thoughts; guilt; feelings of helplessness and separation anxiety; anger, which may be directed at one's spouse, other children, religion, and/or health care professionals; and, reconciliation (Futterman & Hoffman, 1984). Reconciliation involves developing a perspective which preserves the family's confidence in the worth of the child's life; redefining the child's death in order to

reduce its overwhelming implications; seeking consolation from the child's past and present life; and finding appreciation in the quality of care the child received at the time of diagnosis and duration of survival (Futterman & Hoffman, 1984).

The third and final task, maintaining need-fulfilling relationships within the family, refers to the difficult task of detaching oneself from the dying child. Detachment seems related to parental expectations about when the child will die (Futterman & Hoffman, 1984). As not all decisions to forgo life-support result in death, physicians must also prepare parents for the emotional hazards of detachment when a child survives longer than expected. This outcome inevitably necessitates parents be prepared to reconsider similar decisions, as well as develop means of adjusting to prolonged care on the paediatric intensive care unit .

Parental Stress and the Paediatric Intensive Care Unit

Advances in life-saving technology have meant many critically ill children receive much of their treatment in paediatric intensive care units (PICU). While successful in reducing mortality rates, technological machinery found in the PICU continues to emit an atmosphere of criticality and stress for both parents and children (Carter & Miles, 1983; Miles, Carter, Riddle, Hennessey, Eberly, 1989; Riddle, Hennessey, Eberly, Carter, & Miles, 1989). Identified parental stressors include: changes in parent role as caregiver (Jay, 1977); fear of outcome of admission and death, anxiety about new-strange environment (Miles, 1979); initial shock and disbelief, later feelings of helplessness and guilt (Rothstein, 1980); sights and sounds of the unit (Lewandowski, 1980); uncertainty

(Mishel, 1983); and child's pain, child's altered communicative abilities, and parents' inability to protect and help their sick child (Miles et., 1989; Riddle et al., 1989).

Pædiatric intensive care units are stressful environments for children, parents, nurses, and physicians. Although today's parents have come to expect advanced medical technology in hospital settings (Riddle et al., 1989), such expectations do not lessen the impact of parenting a child hospitalized in an intensive care unit. Therefore, physicians must be aware of parental stress when discussions to forgo a child's life-supporting treatment are initiated.

Forgoing Life-Sustaining Medical Treatment

With increases in the life-expectancy of infants weighing less than 1500 grams (Lowenthal, 1989), the issue of forgoing infant life-support has been ignited. As these infants have various congenital anomalies and handicaps, their quality of life may be poor. Infants may also be left so severely impaired they are not aware of themselves, or others around them (Duff & Campbell, 1973). Therefore, Duff and Campbell (1973) suggested infant euthanasia be a viable option when treating profoundly impaired infants.

Forgoing life-support from infants has long been a topic of philosophical debate. It has been argued that competent individuals who are terminally ill or profoundly disabled have the right to refuse life-sustaining treatment (Veatch, 1976). Veatch (1976) also argued it could be morally acceptable for a person to refuse life-supporting treatment for another individual (e.g., neonate) who is not competent to make such a decision. According to Veatch (1976), such a situation necessitates the presence of two factors.

First, the treatment must be likely to prolong life, but not correct the underlying condition. Second, judgements concerning future quality of life must take into account only the infant's best interests, not the desires of others. Others have suggested infants be allowed to die if they would likely experience a short life of intolerable pain (Engelhardt, 1975), or if they were kept alive only to live a life cut off from social interactions, incurable pain, and inevitable death in infancy (Jonsen & Garland, 1976).

Advocates for the forgoing of life-support have argued that the consequences associated with the birth of a severely handicapped infant could cause financial, emotional, and social problems beyond the family's available resources (Harrison, 1986). In finding elevations in financial stress (Lowenthal, 1987) and caregiver distress (Breslou, Saruch, & Mortimer, 1982) when a handicapped infant was born, some researchers concur with these arguments. However, others have proposed that family characteristics prior to the infant's birth determined the extent of family impact (Blackard & Brash, 1982).

Forgoing life-sustaining treatment from an infant involves determining the quality and value of relationships a profoundly disabled infant might have, in what may or may not be, a short life-span. Those against forgoing treatment have argued infants have the right to necessary medical care, irrespective of quality of life judgements (Ramsey, 1978). A measure such as forgoing life-support threatens to undermine the commitment of parents to provide necessary care and support for their children (Fletcher, 1980). Fletcher (1980) also asserted society's dignity depends on the manner in which care is provided to severely ill infants, regardless of the perceived quality of the infants' lives.

The term "forgo" refers to withdrawing a treatment already started, as well as withholding the initiation of a treatment. When a decision is made to withhold life-support from an infant or child, a "do not resuscitate" or "DNR" order is written. DNR orders state that when and if the child's heart stops, certain interventions will not be initiated. Interventions generally include chest compressions (CPR), and limited or prohibited use of life-supporting medications, such as vasoactive drugs. A DNR order does not restrict palliative measures, such as analgesics. Given the complexity of such a decision, a DNR order is designed to meet the specific needs of each child.

The decision to withdraw life-support is ethically equivalent to withholding life-support, but slightly different in practice. Once the decision is made to withdraw life-support, steps are immediately taken to discontinue the appropriate medications and remove the child from the respirator. A DNR order is not explicitly written, although one is implied, in that when the child's heart stops, life-support is not re-instituted.

Preliminary assessments of previous DNR discussions suggest a "good" DNR decision would be characterized as: (a) appropriate to the child's medical circumstances; (b) based on the values of parents, not staff; (c) clearly communicated to parents; (d) easily changed if circumstances surrounding the child's illness changed; (e) results in a death that both family and staff perceive as dignified and respectful; and (f) allows parents and staff to remain comfortable with the DNR decision months and years later.

Attributes which might impede or interfere with the making of a "good" DNR decision include: (a) the urgent and critical nature of the illness/situation; (b) complexity

of the medical situation, including uncertainty of diagnosis and prognosis; (c) differing value systems within the health care team, and between physicians and parents; (d) unknown impact of current in-hospital death procedures on the grieving process of parents (i.e., do current practices which encourage parents to be present and hold their child at time of death, help or hinder the grief process); and (e) communication problems (e.g., inconsistencies in information charted by staff, poor communication at shift changes, staff unavailability to parents).

The decision to withhold/withdraw life-support from a neonate, infant or child is always difficult, but unfortunately not infrequent. In one study, 18 of 144 (13%) neonates died with an understanding not to resuscitate (Lantos, Miles, Silverstein, & Stocking, 1988). A DNR order was written for 5 of the 18 neonates; for 9 neonates, documentation to withhold was found in physician's notes, but a DNR order was not written; and for 4 neonates, there was no documentation, but CPR was not initiated (Lantos et al., 1988). In another study, withdrawal of life-support was discussed among the medical staff for 75 children, and with the parents of 51 of those children (Whitelaw, 1986). Of those parents, 47 agreed to discontinue life-support, resulting in 47 of 158 deaths (30%) occurring after a withdrawal (Whitelaw, 1986). DNR decisions are made more difficult given that once life-support is withdrawn or withheld, the child may not immediately die.

Current literature addressing decisions to forgo treatment from paediatric patients is primarily comprised of studies designed to examine: ethical issues involved in decision-making (Jonsen, Phibbs, Tooley, & Garland, 1975); physician guidelines indicating when

withholding/withdrawing may be appropriate (Perry, Schwartz, & Amchin, 1986); survival rates and resource utilization (Doyal & Wilsher, 1994; Duff & Campbell, 1973); and parent involvement in decision-making (Pinch & Spielman, 1990). Investigators of parental participation in decision-making have indicated parents' role in decision-making is curtailed by a hierarchical ordering of the physician-parent relationship (Pinch & Spielman, 1990). Physicians are said to exert control by deciding when interactions occur, controlling the amount and type of information; using medical jargon and technological language; and addressing parents informally while maintaining formal titles themselves (Clark, Potter, & McKinlay, 1991; Maynard, 1991). Decisions relating to the forgoing of a critically ill child's life-support were not included in these investigations of parental participation in decision-making. Few investigators have examined parental perceptions following their involvement in decisions related to their child's death.

Thus far, it appears only one study has been designed to evaluate parent experiences with decision-making and death. Interviews were conducted with two sets of parents whose infants had been treated in the hospital's neonatal intensive care unit. The neonates had been expected to die, but did not (Schlommann & Fister, 1995). These parents felt the inopportunity to engage in parenting-behaviours (e.g., feeding, holding crying baby, spending time with baby) decreased their sense of loss, while simultaneously increasing their sense of guilt (Schlommann & Fister, 1995). Regarding decision-making, these parents' desire to be more involved was allayed by feelings of ignorance, limited choices, and a concern for responsibility of outcomes (Schlommann & Fister, 1995). When

asked to consider a hypothetical situation in which a decision was made to withdraw life-support, these parents answered on abstract and personal levels. Abstractly, they discussed the need to limit treatment, as not all babies can be saved; personally, they stated they would choose aggressive treatment for their child, as they could not conceive a situation so grave they would terminate their child's life-support (Schlommann & Fister, 1995).

Given this scarcity of research, little is known about the consequences associated with the initiation and aftereffects of "DNR" discussions. A "DNR" discussion is defined as having occurred when there is a discussion between parents and physicians regarding the decision to withdraw or withhold a child's further life-sustaining treatment. Investigators have not examined when discussions to forgo life-support are initiated (e.g., diagnosis, prognosis of illness, stage of illness, parents' readiness to discuss prognosis, and rationale behind initiation of discussion) nor how discussions are conducted (e.g., initiator of discussion, frequency of parent-physician meetings, parents' understanding of illness, parents' awareness of their rights and responsibilities, and parents' comfort with decision). In the aftermath of DNR discussions, investigators have neither examined the factors influencing parents in their decision (e.g., perception of child's pain, understanding of prognosis, stress of PICU environment, quality of life judgements) nor the long-term impact on the families (e.g., surviving sibling adjustment, subsequent parent-child interaction, differences in maternal and paternal adjustment, parent psychological status).

Consequently, this thesis was initiated to develop a preliminary understanding of family adjustment following parent-physician decisions to forgo life-sustaining treatment from their critically ill child. The DNR decision-making process and its consequences were evaluated through several standardized questionnaires and a parent-researcher interview. Outcome variables of interest were: maternal perception of stress arising from the PCCU environment, maternal psychological symptom status, sibling adjustment, family functioning, and maternal perception of current hospital decision-making procedures.

The Paediatric Critical Care Unit (PCCU) in the Children's Hospital of Western Ontario (CHWO)/London Health Sciences Centre, is equipped to provide care to a maximum of 13 patients, ranging in age from premature infant over 1700 grams to 17 years. Staff consists of 4 attending physicians, 2-4 critical care fellows, 2-4 residents, and critical care nurses, of whom one is assigned to each child as primary nurse. Additional treatment and support comes from respiratory technologists, social workers, psychologists, and chaplain services. In collaboration with the staff of CHWO/LHSC, participants were 40 families of infants and children treated in the PCCU during calendar years 1994 through 1995. Data was collected retrospectively, 6 to 12 months after the child's hospitalization in the PCCU. In a 1993 CHWO/Psychology Department study, the FACES-II measure of family functioning was completed by 106 mothers of chronically ill children during the children's out-patient clinics; this data was also included in this thesis.

Mothers of primary interest were those whose: (a) child died in the PCCU following a discussion to forgo life-support; (b) child died in the PCCU, but a discussion

to forgo life-support did not occur; and (c) child survived their PCCU stay, despite the fact that at least one member of the health care staff felt the child's symptoms were sufficiently severe to merit a discussion to forgo life-support. Eighteen of the participating families had at least one other child, one of whom was between 3 and 5 years of age; siblings between 3 and 5 years were included in a component of this thesis designed to assess sibling adjustment.

It was of interest to determine if parent involvement in a DNR discussion would contribute to better adjustment and acceptance of the PCCU outcome. In cases where death appears imminent, DNR discussions may give parents more information and opportunities with which to reconcile their child's impending death. In cases where the child could survive, DNR discussions may provide parents with more information, a greater understanding of their child's medical condition, and the opportunity to consider the long-term effects on the child and family; as such DNR discussions may contribute to better family adjustment.

It would be useful to have more knowledge about the family functioning of critically and chronically ill groups. The circumstances surrounding life-threatening critical illnesses and DNR discussions may have long-term effects on the functioning of families of critically ill children (e.g., parent-child interaction, sibling behaviours, emotional impact on parents). Likewise, chronic but not immediately life-threatening ailments, may also have long-term effects on the families of chronically ill children (e.g., sibling and parental adjustment, financial stress, employment limitations). Although the illnesses may differ in

their short- and long-term duration, the potentiality for problematic family adjustment justifies comparisons of family functioning across these groups.

Given that the PCCU-environment invokes varying degrees of stress in parents, it was expected that impact of the stress would be expressed in several interdependent ways. To explore this possibility, several questions were examined. Correlational analyses were performed to determine if PCCU-focused stress manifested itself as a psychological symptom. Correlational analyses were also performed in order to associate maternal psychological symptom status with the behaviours of surviving siblings. As aspects of the PCCU environment and decision-making experience may be associated with maternal psychological symptom status and sibling behaviours, adjustment of the family unit may be hindered; therefore, family functioning was examined in relation to these measures.

Method

Participants

Participants were mothers of critically ill ($n = 40$) and chronically ill ($n = 106$) infants and children treated at the Children's Hospital of Western Ontario/London Health Sciences Centre. Critically ill children (mean age at death or discharge = 3.91 years; range = 0 days to 16.45 years) were hospitalized in the Paediatric Critical Care Unit (PCCU) during calendar years 1994 through 1995. Chronically ill children (mean age at clinic visit = 11.35 years; range = 7 to 16 years) frequented various CHWO/out-patient clinics during calendar year 1993. An extensive age distribution is presented in Table 1.

Mothers of critically ill children were chosen from one of the following 3 groups:

- 1) child died in the PCCU following a discussion to forgo life-support ($n = 18$; M = 3.91 years; range = 0 days to 14.47 years);
- 2) child died in the PCCU, but a discussion to forgo life-support did not occur ($n = 6$; M = 5.49 years; range = 0 days to 11.98 years);
- 3) child survived their PCCU stay, despite the fact that at least one member of the health care staff (e.g., nurse) felt the child's symptoms were sufficiently severe to merit a discussion to forgo life-support ($n = 16$; M = 3.26 years; range = 0 days to 16.45 years).

Discussions to forgo life-support did not occur for children in Group 2 for one of two reasons: (a) children were declared brain dead, thus making life-support futile; or (b) at some point during the child's PCCU stay, resuscitative efforts were unsuccessful and ceased by physicians without parents' prior involvement. Critically ill children were

diagnosed with one of the following ten medical problems: infectious disease, cardiac, hypoxic ischemic event, neoplastic disorder, respiratory, congenital anomalies, prematurity, trauma, central nervous system, gastrointestinal disorder. A distribution of diagnoses is presented in Table 2.

The criteria for including mothers in one of the 3 groups were: (a) child hospitalized in PCCU 6 to 12 months prior to parent-researcher interview; and (b) child's family physician contacted to determine if he/she knew of any reason why the family should not be invited to participate. Participants were identified through the 1994-1995 minutes of Patient Care Review, PCCU charts, and PCCU medical staff. An additional 20 mothers meeting the participant criteria were not included, as they were untraceable or lived out of geographical range. Ninety percent of mothers agreed to participate when contacted. Eighteen of the participating mothers had other children, at least one of whom was between 3 and 5 years of age. Siblings 3 to 5 years of age were included in a component of this study designed to evaluate sibling adjustment.

In a 1993 CHWO/Psychology Department study, the FACES-II scale was completed by mothers of chronically ill children ($n = 106$) during the children's regular out-patient clinic visits. These data were used in the present study. Children in Group 4 were characterized by one of the following five diagnoses: asthma ($n = 29$; $\bar{M} = 10.43$ years); neoplastic ($n = 18$; $\bar{M} = 10.55$ years); gastrointestinal ($n = 9$; $\bar{M} = 11.88$ years); cystic fibrosis ($n = 21$; $\bar{M} = 12.19$ years); and diabetes ($n = 29$; $\bar{M} = 11.93$ years).

For each of the four groups, descriptive statistics were compiled for several demographic variables: gender of target child, age of target child (at death for Groups 1 and 2; at discharge for Group 3; at time of clinic visit for Group 4), number of days spent in PCCU, number and mean age of siblings of the target child, mother's age, mother's highest attained education level, mother's current employment level, and family social status level (minimum-maximum range: 8-66; Hollingshead Social Status Index, 1975). The data for Groups 1 to 3 were collected in 1994 and 1995, while Group 4 data were collected in 1993. Group means, standard deviations, and/or percentages for each of the variables are presented in Table 3.

One-way analyses of variance were conducted to determine if the groups differed demographically. The Groups did not differ in number of siblings, mother's highest attained education level, nor family social status level. As expected given their survival status, children in Group 3 spent more time in the PCCU than did children in Groups 1 and 2, $F(3,145) = 30.89, p < .01$. Children in Group 4 were older than children in Groups 1, 2 and 3, $F(3,145) = 46.93, p < .01$; therefore, it was not surprising that the siblings, $F(3,118) = 6.32, p < .05$, and mothers, $F(3,144) = 10.59, p < .01$, of children in Group 4 were also older. In comparison to mothers in Groups 1, 2 and 3 who were employed part-time or full-time, mothers in Group 4 were part-time employees or unemployed, $F(3,143) = 3.90, p < .05$; the nature of the children's chronic illnesses may necessitate adaptability in maternal employment (e.g., home care, frequent hospital visits).

Measures

The following instruments, for which literature reviews appear in Appendix A and copies appear in Appendices B to E, were used to assess current family functioning, maternal stress arising from the paediatric critical care unit, maternal perception of the hospital decision-making experience, maternal psychological symptom status, sibling behaviours, and mother-child interaction.

Family Adaptability and Cohesion Evaluation Scales-Version II: FACES II (Olson, Bell, & Portner, 1982). This 30-item self-report scale is based upon the Circumplex Model of Marital and Family Systems (Olson, 1986). Respondents' answers yield measures of family adaptability and cohesion, recognized factors in family functioning. The cohesion dimension ranges from disengaged through separated, connected, and very connected. The adaptability dimension ranges from rigid through structured, flexible, and very flexible. Scores range from 15-80 for cohesion, and from 15-70 for adaptability; high scores indicate optimal cohesion and adaptability levels. Cohesion and adaptability scores are combined to yield 4 categories of general family functioning: extreme, mid-range, moderately-balanced, and balanced (Olson et al., 1982; Olson, 1991). Balanced-type families are those scoring high on the dimensions and functioning optimally; extreme-type families are those scoring low on the dimensions and exhibiting poor family functioning. Cronbach alpha coefficients are .78 for adaptability, .87 for cohesion, and .90 for the total scale (Olson et al., 1982). Test-retest reliability is .83 for cohesion and .80 for adaptability (Olson et al., 1982). Concurrent validity of .93 and .79 were found for

cohesion and adaptability with the Dallas Self-Report Family Inventory (Olson et al., 1982).

Parental Stressor Scale: Paediatric Intensive Care Unit: PSS:PICU (Carter & Miles, 1983). Measuring both physical and interpersonal dimensions of the intensive care unit, this 36-item instrument was developed to assess parent perceptions of stress stimuli in the PICU. Dimensions included in the scale are: Child's Appearance, Sights and Sounds, Child's Behaviour and Emotions, Medical Procedures, Staff Communication, Parent Role Alteration, and Staff Behaviours. Parents, either individually or together, are asked to rate their level of stress for each item using a 5-point scale, ranging from "*0 - not experienced*", "*1 - not stressful*" to "*5 - extremely stressful*"; the higher the score, the higher the perceived stress for a given item. Nursing specialists were used as consultants and pilot studies were conducted to assess content validity of the PSS:PICU. Test re-test reliability coefficients for the dimensions ranged from 0.58 to 0.92 (Carter & Miles, 1983). Alpha coefficients ranged from 0.72 to 0.99, with an alpha coefficient of 0.95 for the total instrument (Carter & Miles, 1983).

Brief Symptom Inventory: BSI (Derogatis, 1975). The BSI is a 53-item self-report inventory designed to reflect the psychological symptom patterns of community non-patient respondents, as well as psychiatric and medical patients. It is not a measure of personality, but rather a measure of current, point in time, psychological symptom status. Item distress is rated on a 5-point scale, ranging from "*0 - not at all*" to "*4 - extremely*". For each respondent (e.g., mother), scores are generated for 9 symptom dimensions

(Somatization, Obsessive-Compulsive, Interpersonal Sensitivity, Depression, Anxiety, Hostility, Phobic Anxiety, Paranoid Ideation, and Psychoticism). High scores indicate greater symptom intensity. The 53 items can also be combined to yield 3 indices of global distress (Global Severity Index, Positive Symptom Distress Index, and Positive Symptom Total). Using gender-keyed norms, the BSI may be interpreted in 3 ways: individual symptomatology, syndromal representation, and general measure of psychological status. Internal consistency coefficients for all 9 dimensions range from .71 on Psychoticism to .85 on Depression (Derogatis, 1982). Test-retest coefficients range from .68 for Somatization to .91 for Phobic Anxiety (Derogatis, 1982). Global indices are stable: .90 for Global Severity Index, .87 for Positive Symptom Distress Index, and .80 for Positive Symptom Total (Derogatis, 1982).

Child Behaviour Checklist; CBCL (Achenbach, & Edelbrock, 1983). This measure is usually completed by the participant's primary caregiver. The 120-item standardized scale assesses 2 dimensions, Total Behaviour Problems and Competence. Total Behaviour Problems are sub-divided into 2 broad-band factors, Internalizing and Externalizing Behaviours. Competence is sub-divided into Activities, Social, and School Competence. Each item is rated for its frequency of occurrence, "0 - not at all" and "2 - very often". Low scores on the Behaviour Dimensions and high scores on the Competency Dimensions are preferable. The CBCL has separate age norms for boys and girls. Activity, Social, and School competence scores are not completed for children under 4 years of age. It has a test-retest reliability of .89, and is a valid discriminator of

maladjusted and poorly achieving children (Achenbach & Edelbrock, 1983).

Mother-Child Dyads. To evaluate mother-child interaction, mother and child behaviours and verbalizations during a problem-solving task were examined. This task employed the WPPSI Block Design Subtest (designed for children between the ages 3 and 6 years). As determined by the child's age, mother and child were given one easy and one difficult design to complete. A 10-minute time limit was given in which to complete each design. An audio-recording was made along with a detailed protocol of all mother and child behaviours and verbalizations. Once behaviour records were completed for each mother-child dyad and checked against the audio-recorded data, they were scored using Rosen and D'Andrade's (1959) categories of behaviours for scoring parent-child interactions in the problem-solving setting. In the Rosen and D'Andrade (1959) system, 10 maternal behaviours and 4 child behaviours are scored; behaviours are scored in terms of positive and negative interactions and verbalizations. The categories by which behaviours are scored appear in Appendix F.

Peabody Picture Vocabulary Test-Revised; PPVT-R (Dunn & Dunn, 1981). This instrument is an individually administered measure of vocabulary, designed for persons 2.5 through 40 years of age. As part of this study, the PPVT-R was administered to siblings between 3 and 5 years old. Following testing, which required 10-20 minutes, raw scores were converted to age-referenced norms and used as an indicator of children's basic cognitive functioning. The PPVT-R possesses an internal consistency reliability of .81 and a test-retest reliability of .82 (Dunn & Dunn, 1981).

Parent-Researcher Interview. Interviews were conducted with mothers whose child was hospitalized in the PCCU. Mothers were asked open-ended questions which addressed their perception of four decision-making components: (a) understanding of child's illness; (b) communication with the health care staff; (c) amount of control over decisions/treatments; and (d) overall comfort with the eventual outcome. Questions within each component varied depending on the circumstances surrounding the outcome of each child's illness. Appendix G contains a version of the interview designed for mothers of children about whom a discussion to forgo life-support occurred and the child subsequently died (Group 1). Copies of the questions asked of mothers in Groups 2 and 3 appear in Appendices H and I.

Each component of questions was followed by a series of non-standardized questions (Appendix G) developed for use in the parent interview. Mothers answered using a rating scale of 1 to 5, where high scores indicated optimal maternal perception. Each component differed in the number of questions within each component. Overall decision-domain (e.g., Understanding) scores were obtained by summing the individual response scores and dividing that sum by the number of questions in the component. Qualitative information obtained from the interview data were not analyzed for this thesis; analyses were performed only on mothers' answers to the quantitative interview questions.

Procedure

Upon identification of mothers meeting participant criteria (i.e., group membership and physician approval), a critical care physician contacted the mothers to briefly describe

the study and ascertain their interest in participating. Mothers providing verbal consent were mailed a package which included the letter of information (Appendix J) and the standardized questionnaires (Family Adaptability and Cohesion Evaluation Scales: II, Parent Stressor Scale: Paediatric Intensive Care Unit, Brief Symptom Inventory, and Child Behaviour Checklist). One week later, mothers were contacted by a Research Assistant to arrange an appointment for the interview.

All interviews took place within the mother's home. At this time, the consent form was signed (Appendix K), family demographic information was collected (Appendix L), and the completed questionnaires reviewed. Siblings between 3 to 5 years were then administered the Peabody Picture Vocabulary Test-Revised (PPVT-R). Mother and sibling then jointly completed the mother-child dyad task (i.e., WPPSI Block Design Subtest).

Upon completion of the mother-child dyad task, the interview was initiated. With permission, all interviews were audio-recorded and lasted between 1 and 2 hours. Mothers were informed they were under no obligation to complete all questionnaires, answer all interview questions, nor to complete the interview. Upon conclusion of the interview, mothers were asked to complete a second BSI. This was done as a means of assessing maternal psychological symptom status both before and after the interview. Mothers were then given the opportunity to ask questions of the Research Assistant and arrange for further counselling with the hospital's Psychology and Paediatric Departments.

Results

This exploratory study was initiated to develop a preliminary understanding of family adjustment following parent-physician decisions to forgo the life-support of a critically ill child. Although data were collected over an 8-month period, obtaining a sample large enough for statistical analyses was hindered by the time required to identify the sample, recruit participants, and collect data. A fourth group of mothers of chronically ill children, was included only in the analysis pertaining to the FACES-II measure of family functioning. Because all but one of the analyses were based on a small and unequally distributed sample (at most, 40 participants), a .10 significance level was adopted. The Pillais approximate F-test is reported for multivariate analyses.

Family Functioning

A four Group MANOVA was performed to assess the relationship between Group and family functioning. The dependent measures were Cohesion and Adaptability. Analyses were based on 40 participants in the critically ill groups and 106 in the chronically ill group. Multivariate effect for Group was significant, $F(6,284) = 2.04$, $p = .06$. Group means and FACES-II interpretation guidelines are presented in Table 4. Although all Groups scored within the "connected" Cohesion range, inspection of the means reveals that Group 1 families were less cohesive than Group 2, 3, and 4 families; families of children surviving their critical illness were the most cohesive. With respect to Adaptability, means reveal that Group 1 families scored within the structured range, as opposed to the more optimal "flexible" range in which Group 2, 3, and 4 families scored;

families of children with a chronic illness were the most adaptable.

Maternal Perception of Hospital Decision-Making Experience

Mothers ($n = 37$) rated their perception of the hospital decision-making experience on a series of non-standardized questions developed specifically for use in the parent-researcher interview. Aspects of the decision-making experience encompassed 4 domains: Understanding, Communication, Control, and Comfort. The questions, which varied in number for each domain, were answered on scales of 1 to 5; higher scores indicated optimal maternal perception. Domain scores were obtained by summing the individual response scores and dividing that sum by the number of questions in each domain. A three Group MANOVA was used to assess group differences in maternal perception for the four dependent measures: Understanding, Communication, Control, Comfort. Multivariate effect for Group was not significant, $F(8,64) = .81, p = .60$. Grand means for each decision-making domain were: Understanding ($M = 3.82, SD = .75$); Communication ($M = 4.13, SD = .74$); Control ($M = 4.29, SD = .54$); and Comfort ($M = 4.01, SD = .98$). In the absence of prior norms, mothers perceived their level of Understanding as "average to good", while levels of Communication, Control, and Comfort were perceived as "good".

Maternal Stress and the Paediatric Critical Care Unit (PCCU)

Using the PSS:PICU as a measure of stress arising from the PCCU environment, mothers ($n = 40$) rated each stress dimension on a scale of "1 - not stressful" to "5 - extremely stressful". A three Group MANOVA was performed to assess the relationship

between Group and maternal perception of PCCU-related stress. The dependent measures were: Child's Appearance, Sights and Sounds, Child's Behaviours, Medical Procedures, Staff Communication, Parent Role Alteration, and Staff Behaviours. Multivariate effect for Group was not significant, $F(14,64) = .38$, $p = .98$; groups did not appear to differ in maternal perception of the stress raised by various aspects of the PCCU environment. Overall sample mean for Total PCCU Stress was: $M = 3.41$ ($SD = .87$). Guidelines for the PSS:PICU indicate scores between 3 to 4 fall within the moderate to very stressful range; in the absence of standardized norms, the overall mean indicates mothers perceived the Total PCCU experience as moderately to very stressful.

Maternal Psychological Symptomatology

The Brief Symptom Inventory was completed by 29 mothers both prior to and upon completion of the parent-researcher interview. Eleven mothers opted not to complete the BSI. A three Group MANOVA with repeated measures (pre- versus post-test) was conducted to determine the relationship between Group and maternal psychological symptomatology. The dependent measures were: Somatization, Obsessive-Compulsive, Interpersonal Sensitivity, Depression, Anxiety, Hostility, Phobic Anxiety, Paranoid Ideation, and Psychoticism. Multivariate effect for Group reached significance, $F(18,38) = 1.73$, $p = .07$; Group 2 ($n = 6$) mothers exhibited a more intense psychological symptomatology than did mothers in Groups 1 ($n = 12$) and 3 ($n = 11$). Using the symptom scores to obtain a measure of Global Severity Index (GSI), Group means were: Group 1 ($M = .66$, $SD = .89$, $z = 1.16$, $p > .05$); Group 2 ($M = 1.82$, $SD = .85$, $z = 4.90$, p

< .001); and Group 3 ($\underline{M} = .99$, $\underline{SD} = .93$, $z = 2.22$, $p < .05$), while $\underline{M} = .30$ ($\underline{SD} = .31$) is the test norm. GSI Group means were above the normative sample for mothers in all 3 Groups, but particularly for mothers in Group 2. The effect of repeated measure (pre-versus post-test) was not significant, $F(18,38) = .45$, $p = .962$; reflecting stability in maternal psychological symptomatology over time.

Mothers in Group 2 ($n = 6$) not only exhibited a higher symptom severity index than mothers in Groups 1 ($n = 12$) and 3 ($n = 11$), their scores for the individual symptoms were also consistently higher in intensity. At pre-test, all nine symptoms were rated more intensely by mothers in Group 2 than by mothers in Group 1. Also at pre-test, mothers in Group 2 rated eight of nine symptoms more intensely than did mothers in Group 3; mothers in Group 3 in turn rated eight of nine symptoms more intensely than mothers in Group 1 (see Figure 1). Assuming the independence of these measures, the likelihood of this 2-3-1 Group symptom intensity pattern occurring for seven of the nine dependent measures by chance was small, 5.63×10^{-4} (binomial probability). The 2-3-1 Group intensity pattern occurred for all 9 dependent measures at post-test (see Figure 2); the likelihood of this pattern occurring by chance was even more remote, 5.95×10^{-7} (binomial). Further inspection reveals that pair-wise comparisons in group symptomatology were amazingly consistent. In 18 of 18 comparisons, mothers in Group 2 ($n = 6$) rated each symptom more intensely than did mothers in Group 1 ($n = 12$), 7.62×10^{-6} (binomial). In 17 of 18 comparisons, symptoms for mothers in Group 2 were more intense than symptoms for mothers in Group 3 ($n = 11$), 1.44×10^{-4} (binomial). Also in 17

of 18 comparisons, mothers in Group 3 scored each symptom more intensely than mothers in Group 1, 1.44×10^{-4} (binomial). These results indicate that death which is unexpected and not preceded by a DNR discussion appears to contribute to increased intensity of maternal psychological symptomatology, while involvement in a DNR discussion appears to contribute to reduced symptomatology intensity.

Sibling Behaviours

Mothers completed Child Behaviour Checklists (CBCL) for surviving siblings between 3 and 5 years old ($n = 18$). Mean scores for the Behaviour Problems and Competency dimensions are presented in Table 5. Analyses for Behaviour Problems were based on 18 participants. However, as the CBCL scoring profile does not generate Competency scores for children under 4 years old, analyses for Competence were based on 10 participants. A three Group MANOVA was performed to assess group differences in maternal perception of siblings' behaviour problems. The dependent measures for the Behaviour Problems dimension were: Internalizing Behaviours and Externalizing Behaviours. Multivariate effect for Group was significant, $F(4,30) = 2.28, p = .084$. Where lower scores indicate fewer problematic behaviours, these results indicate that mothers of children who died following a DNR discussion perceive their surviving children to be exhibiting fewer Internalizing and Externalizing Behaviours than do mothers of siblings in Groups 2 and 3. Standardized norms indicate mean scores for Behaviour Problems for siblings in Group 1 were within the normal range. Norms also indicate that scores between 60-64 are identified as borderline clinically problematic, while scores

above 65 are identified as clinically problematic; mean scores for siblings in Group 2 and 3 were within the borderline clinical range. A three Group MANOVA was also performed to assess Group differences in Competence. The dependent measures were: Activity and Social Competence. Multivariate effect for Group was not significant, $F(4,14) = .58$, $p = .68$. As indicated by standardized norms, group means were within the normal range.

As additional measures of sibling behaviours, the PPVT-R and WPPSI Block Design Subtest were administered to siblings between 3 and 5 years of age. Analyses were based on 9 children (6 in Group 1; 3 in Group 3); mean age at time of data collection, $M = 3.58$ years. Group differences for the PPVT-R were not significant, $F(1,8) = .018$, $p = .89$. Overall sample mean score was: $M = 55.2$ ($SD = 3.31$). Conversion to standardized norms indicated raw scores were within the normal range.

Audio-recorded data obtained during completion of the mother-child dyad task was scored using a specific maternal/child behaviour coding scheme (Rosen & D'Andrade, 1959); inter-rater reliability ratings of .88 for maternal behaviours and .92 for child behaviours were obtained. Separate two Group MANOVAs were performed to assess Group differences in maternal and child behaviours. The dependent measures for maternal behaviours were: Approval, Positive Tension, Negative Tension, Positive Evaluation, Enthusiasm, Non-Specific Instruction, and Specific Instruction. Three additional dependent measures (Hostility, Negative Evaluation, and Displeasure) were not included in the analyses, as participating mothers did not exhibit these behaviours. Multivariate effect for Group was significant, $F(7,1) = 1537.39$, $p = .02$. In comparison to mothers in

Group 3, mothers in Group 1 engaged in more positive interactions toward siblings; mothers provided a greater number of Positive Evaluations of child's efforts (e.g., "That's a girl"), and Non-Specific Instructions (e.g., "You can do it with four blocks"). Specific Instructions ("Turn the red one like this") were provided only upon sibling request. The dependent measures for child behaviours were: Requests Aid, Rejects Aid, Positive Tension, and Negative Tension. Multivariate effect for Group was not significant, $F(4,4) = 3.87, p = .11$. Overall sample mean for child behaviours was: $M = 9.0$ ($SD = 6.4$).

Correlational Analyses

As a means of further evaluating family adjustment, the total scores for each of the following instruments were inter-correlated: BSI (GSI: Global Severity Index); PSS.PICU (Total PCCU Stress); FACES-II (Family Type); CBCL (Siblings' Total Behaviour Problems); PPVT-R (Peabody Picture Vocabulary Test Score); TASK (Total Number of Mother-Child Interactions); and DECISIONS (Overall Perception of Decision-Making Experience). Correlations are presented in Table 6. The correlation matrix reveals important points about the dependent measures. First, intensity of maternal psychological symptomatology was positively associated with maternal perception of Total PCCU-related stress. Second, intensity of maternal psychological symptomatology correlated with maternal perception of siblings' total behaviour problems. Third, in a small but significant negative correlation, high PCCU-related stress was associated with low maternal perception of the hospital decision-making experience. Finally, again with small but significant positive correlations, family functioning was associated with a positive

maternal perception of the hospital decision-making experience, as well as the number of positive interactions between mother and child when jointly completing a task.

Discussion

The findings of this study provide information on an area of investigation not extensively evaluated in paediatric psychological research: family psychosocial adjustment following parent-physician decisions to forgo the life-sustaining medical treatment of a critically ill child. Participants were mothers and siblings of children who: (a) died following a discussion to forgo life-support; (b) died without the occurrence of a discussion to forgo life-support; and (c) survived their critical illness despite the fact that at least one member of the health care staff felt the child's symptoms were sufficiently severe to merit a discussion to forgo life-support. Outcome variables of interest were: maternal perception of family functioning; maternal perception of current hospital decision-making procedures; maternal perception of PCCU-related stress; maternal psychological symptomatology; and sibling adjustment.

Family Functioning

Analyses involving the FACES-II indicated families of children who died following a discussion to forgo life-support exhibited lower levels of cohesion and adaptability than did the remaining groups. In the absence of pre-test scores of family cohesion and adaptability, it is difficult to determine if involvement in a DNR discussion lowered these measures of family functioning. Families of children surviving their critical illness appeared to be the most cohesive, while families of children living with a chronic illness were the most adaptable; higher levels of cohesion and adaptability in these families may be attributed to the demands associated with illnesses which are not immediately life-

threatening.

Maternal Perception of Hospital Decision-Making Experience

Involvement in a DNR discussion was examined in relation to maternal perception of medical understanding, communicated information, control over decision-making, and comfort with outcome. In the absence of significant Group differences, the results suggest: (a) mothers in all three Groups perceived each dimension as "good" ($M = 3.8$ and above); and (b) maternal perception of the hospital decision-making experience is neither hindered nor improved by involvement in a DNR discussion. A negative correlation between maternal perception of the hospital decision-making experience and Total PCCU Stress suggests that the lower a mother's perception of overall PCCU-related stress, the better mothers perceive their experience with hospital decision-making procedures. A positive association between the perceived decision-making experience and family type also suggests that the better a mother's perception of the decision-making experience, the higher the family levels of cohesion and adaptability.

Maternal Stress and the Paediatric Critical Care Unit (PCCU)

Group differences in maternal perception of stress arising from the PCCU environment were not significant. On a scale of 1 to 5, where 1 was "not stressful" and 5 "extremely stressful", mothers perceived the overall PCCU experience as moderately to very stressful ($M = 3.4$); maternal perception of PCCU stress does not appear to relate to involvement in a DNR discussion, nor whether the child survived his/her critical illness. Although maternal perception of PCCU stress does not appear related to group

membership, significant correlations between maternal perception of Total PCCU Stress and maternal symptomatology severity are positive. Two inferences may be drawn from this correlation: (a) maternal perception of PCCU-related stress is magnified with increased maternal symptomatology severity; or (b) severely symptomatic mothers may perceive the PCCU environment as more stressful than less severely symptomatic mothers.

Maternal Psychological Symptomatology

Parent-researcher interviews were conducted 6 to 12 months following the child's hospitalization in the PCCU. Mothers completed the Brief Symptom Inventory one to two weeks prior to the interview, and then again immediately following the interview. Differences in maternal symptomatology at pre- and post-interview completion of the BSI were not significant. This indicates that maternal psychological symptom status remained stable for one or more weeks, and was not intensified by participation in the parent-researcher interview. Group differences in maternal symptomatology indicated mothers involved in a DNR discussion exhibited a less intense psychological symptom status than mothers not involved in a DNR discussion. Overall, mothers of children who died without a DNR discussion generated a more intense symptom pattern than mothers whose children died following a DNR discussion, and mothers whose children survived their critical illness; mothers of children who survived their critical illness in turn generated a more intense symptom pattern than mothers whose children died following a DNR discussion.

Although mothers in each of the three Groups generated symptom severity indices which ranged from 1 to 5 standard deviations above normal, mothers of children who died

without the occurrence of a DNR discussion generated the most intense severity index. The deaths of these children followed traumatic brain injuries, or unsuccessful resuscitative attempts. One could infer that the suddenness of the children's death, age at death ($M = 5.49$ years, range = 0 to 11.98 years), the medical circumstances surrounding the child's death, and/or parents' lack of involvement in decision-making (i.e., no DNR discussion) contributed to the intense symptomatology.

Sibling Adjustment

To assess the adjustment of siblings between 3 to 5 years of age, the following measures were employed: (a) Peabody Picture Vocabulary Test-Revised (PPVT-R), which was administered to siblings by the research assistant; (b) a mother-child dyad task involving the WPPSI Block Design Subtest, which was completed at the time of interview; and (c) the Child Behaviour Checklist (CBCL), which was completed by mothers prior to the interview. Although CBCLs were completed for 18 siblings, data pertaining to the PPVT-R and mother-child dyad task were available for only 9 siblings (6 siblings of children who died following a DNR discussion and 3 siblings of children who survived their critical illness). Given this small and unequally distributed sample, these results must be interpreted with caution.

The PPVT-R was administered as a measure of cognitive functioning. Siblings did not differ in their PPVT-R scores; converted raw scores indicated children were functioning within a normal range. Mother-child interactions were also examined as an indicator of sibling adjustment following the PCCU experience. In comparison to mothers

whose children survived their critical illness, mothers of children who died following a DNR discussion engaged in a greater number of positive interactions with surviving siblings (e.g., approval, positive evaluation, enthusiasm). This finding may be attributed to maternal reports that surviving siblings: (a) feared death for themselves, parents, and other siblings; (b) frequently spoke of death at school; (c) feared hospitals; and (d) had little understanding of death's true implications. A positive correlation between mother-child interaction style and family type may also indicate that the number of positive interactions between mother-child dyads increases with higher levels of family cohesion and adaptability. This is noteworthy given that families who demonstrated the greatest number of positive mother-child interactions were the same families who exhibited the lowest levels of cohesion and adaptability. Although families of children who died following a DNR discussion exhibited low cohesion and adaptability levels, this suggests that the levels were not so low as to disrupt the interaction style between mother and child.

Analyses involving the CBCL data followed a similar pattern; mothers whose child died following a DNR discussion reported fewer Internalizing and Externalizing behaviour problems in surviving siblings than did mothers of children whose sibling survived their critical illness. Behaviour problem scores for siblings of children who died following a DNR discussion were within normal ranges. Internalizing behaviour problem scores for both siblings of children who died without a DNR discussion, as well as for siblings of children who survived their critical illness were within the borderline clinically problematic

range; Externalizing behaviour problem scores were within the borderline clinically problematic range only for siblings of children who survived their critical illness.

Previous researchers indicate that children experiencing the death of a sibling exhibit grief and guilt reactions (Krell & Rabkin, 1979), depression (Blinder, 1972), anxiety (Cairns et al., 1979), and sleep disturbances (Walker, 1989). The Internalizing behaviour scores for siblings of children who died without the occurrence of a DNR discussion suggest that the emotional, physical, and hospital stressors associated with a child's sudden death may have an impact on surviving siblings. This finding is worthy of consideration given that siblings of children who died following a DNR discussion experienced the death of their sibling and yet did not exhibit problematic Internalizing and Externalizing Behaviour scores; one may infer that family involvement in a DNR discussion regarding a death which was anticipated lessened the traumatic effect on siblings. Other researchers indicate that the presence of a chronically ill child places increased demands on siblings (Perrin & MacLean, 1988) while also necessitating adaptation in coping style (Kazak, 1989). Internalizing and Externalizing scores for siblings of children who survived their critical illness are consistent with previous findings that the long-term demands of chronic illnesses have a great impact on siblings. Children surviving their critical illness also spent significantly more days in the hospital's PCCU than did children who died in the PCCU; one may also infer that the extended hospital stay necessitated by the critical illness had an impact on sibling adjustment.

As a measure of maternal rating, the CBCL may accurately reflect the existence of sibling Internalizing and Externalizing Behaviour Problems. However, as a parent-perception based measure, CBCL scores may also reflect inaccuracies in maternal perception, or reflect problems in maternal psychological symptomatology which serve to hinder maternal perception of a child's behaviours. Correlational analyses demonstrated a positive association between maternal psychological symptom status and Total Behaviour Problems exhibited by surviving siblings; although mothers may be accurate in their perception of sibling behaviours, it appears that the more severe a mother's psychological symptom status, the more behaviour problems mothers perceive surviving siblings to exhibit. Analyses also demonstrated a positive correlation between maternal ratings of sibling behaviour problems and maternal perception of the decision-making experience; surprisingly, it appears that the better a mother's perception of the decision-making experience, the more behaviour problems siblings are perceived to display. Although mothers rated their decision-making experience as good, this may suggest that mothers were not truthful in their rating of the decision-making experience; on the other hand, this may also suggest that despite a good experience with hospital decision-making procedures, mothers perceive sibling behaviours to be problematic.

Methodological Limitations and Considerations

Of the 40 mothers who took part in this study, 37 consented to participate in the parent-researcher interview. Of those 37 mothers with other children, 7 mothers opted not to complete CBCLs for surviving siblings ($n = 3$ in Group 1; $n = 2$ in Group 2; $n = 2$ in

Group 3). Other mothers completed the CBCL, but refused the sibling's participation in the PPVT-R and mother-child dyad task ($n = 4$; 1 in Group 1; 1 in Group 2; 2 in Group 3). Reasons for refusal were: (a) respect for sibling's privacy; (b) parents perceived siblings to be having difficulties coping and did not want them reminded of the experience; and (c) parents foresaw the interview as being emotionally difficult and did not want siblings to see them upset.

As a further limitation to sample size, 20 families meeting participant criteria were not included because they lived out of geographical range, or were untraceable following hospital discharge. Five families also refused to participate citing unresolved grief and anger towards hospital as reasons for their refusal; given their anger, these families likely had valuable information which may have improved current hospital decision-making procedures. With respect to the Children's Hospital of Western Ontario/London Health Sciences Centre, only those children living in Ontario's southwestern region are treated; hospitals in the southeastern and northern regions of Ontario may specialize in the treatment of different illnesses, and/or follow different practices with respect to decisions to forgo life-support. Within the PCCU itself, different cultural, religious, and/or medical values of the various critical care specialists may contribute to the manner in which discussions to forgo life-support are conducted. Furthermore, the PCCU treats only premature infants over 1700 grams to adolescents under 18 years old; neonates less than 1700 grams are treated in the Neonatal Intensive Care Unit at another London hospital, where different practices regarding DNR discussions may be followed.

The lack of Group differences at a significance level of .05 may be attributed to two factors: (a) the small and unequally distributed sample; and (b) the measures administered as means of assessing the outcome variables. Although information obtained during the parent-researcher interview was not qualitatively analyzed, mothers expressed anger towards the hospital and concern for current family relationships; this indicates that perhaps the measures were not sensitive enough to the issues under investigation. In addition, parents whether consciously or unconsciously, may have answered the questions in a socially desirable manner rather than in a manner truthful to their family dynamics.

Basic differences in group demographics and family dynamics must also be acknowledged as possible confounds. The manner in which parents made decisions and reacted to the PCCU experience may be affected by: previous life experiences; culture; language barriers; involvement of extended family; religious beliefs; illness prognosis and quality of life judgements; age differences in children at death/discharge, and whether death/illness was anticipated or unexpected.

Finally, it should be acknowledged that efforts were made to compile four groups of families: (a) child died following a DNR discussion; (b) child died without the occurrence of a DNR discussion; (c) child survived his/her critical illness despite the occurrence of a DNR discussion; and (d) child survived his/her critical illness despite the fact that a DNR discussion should have, but did not occur. It proved impossible to implement this initial study design in which the effects of occurrence of a DNR discussion and child's survival status would have been independent variables. There were two

reasons for this failure. First, given the critical nature of the various illnesses, a child's group classification could quickly change with improvement or deterioration in illness prognosis. Second, obtaining a group of children who survived a DNR discussion was not possible. Given the findings obtained in the study, it would appear that physicians may be too conservative in their initiation and inclusion of families in DNR discussions. Only if more discussions are initiated by physicians in the future will it be possible to study a group of children who survived such discussions.

Summary and Conclusions

In summary, families of children who died following a DNR discussion show a tendency to be less cohesive and adaptable than families of children dying without a DNR discussion, families of children surviving their critical illness, and families of children living with a chronic illness. Although mothers did not differ in their perception of stress arising from the PCCU environment, the overall PCCU experience was perceived as being moderately to very stressful. Mothers did not differ in their perception of the hospital decision-making experience; mothers rated their level of Understanding as "average to good", while Communication, Control, and Comfort levels were perceived as "good". The psychological symptomatology of mothers whose children died without the occurrence of a DNR discussion was more intense than the symptomatology of mothers whose children died following a DNR discussion, and mothers whose children survived their critical illness. Overall BSI symptom severity was above normal for mothers in all three Groups, but particularly high for mothers of children dying without a DNR

discussion.

This study also included a component specific to mothers' perceived adjustment of siblings between 3 to 5 years old. Surviving siblings did not differ in cognitive functioning. Mothers of children who died following a DNR discussion engaged in more positive interactions with surviving siblings than did mothers of children whose sibling survived his/her critical illness. Mothers of children who died following a DNR discussion indicated surviving siblings were exhibiting the fewest behaviour problems; behaviour problem scores for these siblings were within the normal range. Internalizing and Externalizing behaviour problem scores for siblings of children who died without the occurrence of a DNR discussion, as well as for siblings of children who survived their critical illness were within the borderline clinically problematic range. In addition to group differences, significant positive correlations were obtained between mothers' psychological symptomatology and their perceptions of both the PCCU-experience and behaviour problems of surviving siblings.

To conclude, it appears that having one's critically ill child hospitalized in a Critical Care facility was a stressful experience for mothers. Generally, families report they have adapted well to their child's medical outcome. However, it appears that both mothers and surviving siblings continue to feel the psychological impact of the child's critical illness or death. The psychological effects appear to be particularly traumatic for mothers and siblings of children who died unexpectedly, and less traumatic for mothers and siblings who had been involved in parent-physicians decisions to forgo life-sustaining treatment.

The findings of this preliminary study suggest there is value in parent-physician discussions concerning the future health of one's critically ill child. Given the ethical limitations associated with conducting research which is either prospective, or based within the paediatric critical care setting, future researchers must continue the assessment of family adjustment to the paediatric critical care experience and any PCCU-related decisions. The scarcity of previous research involving parent-physician decisions to forgo life-support, necessitates that future researchers investigate: differences in maternal and paternal perception of family functioning and sibling behaviours; differences in parental adjustment; and sibling adjustment through additional behavioural measures. The hospitalization of a child in a critical care facility is a terrifying experience for parents and siblings. Consequently, physicians and hospital staff must ensure: (a) parents are aware of all medical options and future possible outcomes; and (b) follow-up services be provided to all families of children treated in the PCCU, regardless of the child's medical outcome.

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Table 1

Age Distribution

	Group 1	Group 2	Group 3	Group 4
Age Groups	(n = 18)	(n = 6)	(n = 16)	(n = 106)
Infant:				
Birth to 12 months	50 %	33 %	56%	
Toddler:				
13 to 35 months	11 %	17 %		
Preschooler:				
3 to 4 years, 11 months	17 %		19 %	
Child:				
5 to 7 years, 11 months			13 %	14 %
Pre-Adolescent:				
8 to 11 years, 11 months		50 %		54 %
Adolescent:				
12 to 15 years, 11 months	22 %		12 %	32 %

Table 2

Distribution of Diagnoses

	Group 1	Group 2	Group 3	Group 4
Diagnoses	(n = 18)	(n = 6)	(n = 16)	(n = 106)
Infectious Diseases	1	1	2	
Cardiac	5		4	
Hypoxic Ischemic Events	3	1	1	
Neoplastic Disorders	1		2	18
Respiratory	2		3	29
Congenital Anomalies	2			21
Prematurity		1	1	
Trauma	1	2	2	
Gastrointestinal Disorders	1			9
Central Nervous System	2	1	1	
Diabetes				29

Table 3

Descriptive Statistics for Demographic Variables

	Group 1		Group 2		Group 3		Group 4	
Demographic Variables	(n = 18)		(n = 6)		(n = 16)		(n = 106)	
Male	61 %		67 %		56 %		51 %	
Female	39 %		33 %		44 %		49 %	
	<u>M</u>	<u>SD</u>	<u>M</u>	<u>SD</u>	<u>M</u>	<u>SD</u>	<u>M</u>	<u>SD</u>
Age (yrs) of Target Child (at death/discharge/clinic)	3.91	5.5	5.49	5.5	3.41	4.8	11.40	2.4
Days in PCCU	7.4	12.9	6.3	11.6	16.4	14.1	n/a	---
Number of Siblings	1.5	1.5	1.3	1.2	1.1	.99	1.3	1.0
Age of Siblings	5.6	5.4	5.0	4.9	4.9	6.5	10.2	6.4
Mother's Age	31.5	10.2	30.8	8.3	29.7	7.2	38.7	6.6
Mother's Highest Attained Education Level								
Elementary	6 %		33 %				7 %	
Grade 9-13	50 %		17 %		27 %		47 %	
Some College	6 %		17 %		20 %		16 %	
College Grad	33 %		17 %		53 %		24 %	
Post-Grad							6 %	
Technical	6 %		17 %					
Mother's Employment Status (at time of data collection)								
Full-Time	44 %		100 %		60 %		45 %	
Part-Time	56 %				40 %		29 %	
Unemployed							26 %	
Family Social Status Level	37.2	17.1	30.7	12.6	39.2	16.1	38.5	11.9

Table 4

Family Adaptability and Cohesion Evaluation Scales: Group Means

FACES-II Dimensions	Group 1		Group 2		Group 3		Group 4	
	(n = 18)		(n = 6)		(n = 16)		(n = 106)	
	<u>M</u>	<u>SD</u>	<u>M</u>	<u>SD</u>	<u>M</u>	<u>SD</u>	<u>M</u>	<u>SD</u>
Cohesion	63.6	12.7	66.0	10.9	69.8	9.8	66.2	7.3
Adaptability	44.4	7.2	46.2	8.2	46.0	8.0	47.9	7.2
Overall Family Type	4.8	1.7	5.3	1.7	5.5	1.5	5.4	1.3

Cohesion: 71 - 80 = Very Connected
 60 - 70 = Connected
 51 - 59 = Separated
 15 - 50 = Disengaged

Adaptability: 55 - 70 = Very Flexible
 46 - 54 = Flexible
 40 - 45 = Structured
 15 - 39 = Rigid

Overall Family Type: 0 - 2.9 = Extreme
 3 - 4.9 = Mid-Range
 5 - 6.9 = Moderately-Balanced
 7 - 9.0 = Balanced

Table 5

Maternal Measure of Sibling Behaviours: CBCL

Child Behaviour Checklist (CBCL) Dimensions	Group 1		Group 2		Group 3	
	M	SD	M	SD	M	SD
<u>Behaviour Problems:</u>	(n = 10)		(n = 2)		(n = 6)	
Internalizing Behaviours	50.8	7.9	63.0	15.5	63.0	9.2
Externalizing Behaviours	43.9	9.3	50.5	24.8	60.0	11.3
<u>Competency Dimensions:</u>	(n = 3)		(n = 2)		(n = 5)	
Activity Competence	51.3	6.3	48.5	9.2	47.2	4.1
Social Competence	52.0	1.7	39.5	12.0	51.0	16.5

Table 6

Inter-Correlations between BSI, PSS:PICU, FACES-II, CBCL, PPVT,
Mother-Child Dyad Task and Decision-Making across Groups 1 to 3

Number of Data Available	Measures	GSI	PICU	CBCL	FACES	PPVT	TASK
29	<u>BSI:</u> GSI	----					
40	<u>PSS:PICU:</u> Total Stress	.37 ^c	----				
18	<u>CBCL:</u> Sibling Behs	.62 ^c	-.04	----			
40	<u>FACES:</u> Family Type	.01	.19	.00	----		
9	<u>PPVT:</u>	.26	-.15	-.43	.22	----	
9	<u>TASK:</u>	-.24	-.24	-.38	.53 ^a	.13	----
37	<u>DECISIONS:</u>	-.15	-.23 ^a	.47 ^b	.25 ^a	-.36	.45

^a $p < .10$

^b $p < .05$

^c $p < .01$

Figure 1. Brief Symptom Inventory:
Maternal Symptomatology at Pre-Test

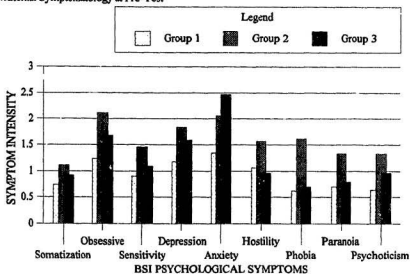
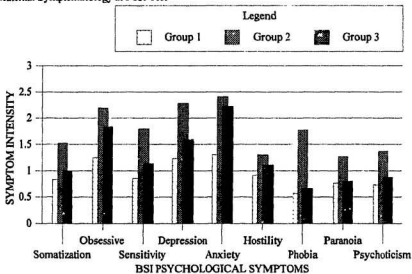


Figure 2. Brief Symptom Inventory:
Maternal Symptomatology at Post-Test



Appendix A

FAMILY ADAPTABILITY AND COHESION EVALUATION SCALES-

VERSION II: FACES-II (Olson, Bell, & Portner, 1982)

The literature on family functioning includes frequent references to Olson's Circumplex Model of Marital and Family Systems (Olson, Sprenkle, & Russell, 1979) and the Family Adaptability and Cohesion Evaluation Scales (FACES-II) (Olson, Bell, & Portner, 1982). The Circumplex Model postulates families high in cohesion and adaptability, recognized factors in family functioning, are exhibiting optimal functioning; those low on the dimensions characterize dysfunctional family functioning.

Used as an evaluative index of family functioning by investigators interested in adjustment to chronic illness, FACES-II allows researchers to analyze families on the cohesion and adaptability dimensions. For instance, a lack of family cohesion has been associated with sibling adjustment problems in families with chronic illness, such as rheumatic disease (Daniels, Miller, Billings, & Moos, 1986; Daniels, Moos, Billings, & Miller, 1987). Family cohesion has also been identified as a predictor of externalizing behaviour problems (Hamlett et al., 1992) in children with sickle-cell anemia (Daniels et al., 1987). In families of children with phenylketonuria, lower levels of adaptability indicated rigid parental control over diet, thus contributing to more effective family functioning (Kazak, Reber, & Snitzer, 1988). In spite of the many studies in which the relationship between FACES-II and chronic illness has been investigated, FACES-II has not been employed as an indicator of family functioning following the death of a family

member.

The literature on family adjustment and overall family functioning has made frequent reference to Olson's three-dimensional Circumplex Model of Marital and Family Systems (Olson, 1986; Olson, Sprenkle, & Russel, 1979; Olson, Bell, & Portner, 1982). Olson and colleagues (1979; 1986) concluded that two theoretical concepts, family cohesion and family adaptability, are major factors in the functioning of any family system. A third concept, family communication, has also been identified as important to the family system. As its primary function is to facilitate movement of the family cohesion and adaptability dimensions, it is not evaluated as a central aspect of the Circumplex Model (Olson et al., 1982).

Defined as the degree to which family members are separated or connected to their family (Olson et al., 1982), family cohesion refers to the emotional bonding and degree of individual autonomy family members experience (Olson, 1986; Olson et al., 1982). Specific concepts used to diagnose and measure this dimension are: emotional bonding, supportiveness, family boundaries, time, friends, decision-making, interests, and recreation (Olson et al., 1982). Family adaptability refers to the extent to which the family system is flexible and capable of change (Olson, 1986). Family adaptability is the family system's ability to change its power structure, role relationships, and relationship rules in response to situational and developmental stress (Olson, 1986; Olson et al., 1982). Elements used to define this dimension include: assertiveness, control, discipline, negotiation style, role relationships, and relationship rules (Olson et al., 1982).

Within the Circumplex Model of Marital and Family Systems, the cohesion and adaptability dimensions each have four levels (Olson et al., 1982). The family cohesion dimension ranges from extreme low cohesion (disengaged) through to separated, connected, and extreme high cohesion (very connected). The family adaptability dimension ranges from extreme low adaptability (rigid) through to structured, flexible, and extreme high adaptability (very flexible).

Combining each of the four levels associated with the cohesion and adaptability dimensions allows identification of 16 specific types of family systems. These specific types are then sub-divided into more general family types: Balanced, Moderately Balanced, Mid-Range, and Extreme. Four of the 16 types are Balanced families; functioning at the most optimal level, Balanced families score highest on both the cohesion and adaptability dimensions. Eight types are Moderately Balanced and Mid-Range family types, scoring high on one dimension but low on the other. The remaining four are Extreme types; the most dysfunctional families, Extreme types score lowest on both dimensions. According to the Circumplex Model, Balanced types are at the highest level, followed by the Moderately Balanced, Mid-Range, and Extreme types (Olson, 1991).

The Family Adaptability and Cohesion Evaluation Scale (FACES-II) was introduced as an evaluative index to accompany the Circumplex Model and has, as of yet, not been standardized. FACES-II is a linear measure, where high scores on cohesion and adaptability indicate optimally functioning family relationships (Balanced) and low scores indicate dysfunctional family relationships (Extreme) (Olson, 1991). More specifically,

high scores on cohesion measure "very connected" families (Balanced) while high scores on adaptability measure "very flexible" families (Balanced) (Olson, 1991).

FACES-II, a 30-item self-report measure, allows individual family members to describe how they currently perceive their family. As it is assumed that not all family members will see their family system in the same manner, multiple family members are encouraged to complete the FACES-II. FACES-II may also be administered twice; once, to determine how family members presently see their family (perceived), and a second time to determine how they would like to see their family (ideal) (Olson et al., 1982). Family functioning in families without children may also be evaluated through administration of the couple-version of FACES-II.

As a means of validating the hypothesis that balanced family types are more functional than extreme types, many researchers have examined families' range symptoms and emotional problems. Clark (1984; cited in Olson, 1986) assessed families with schizophrenics, families with neurotics, families who underwent previous therapy, and a no-therapy control group. As hypothesized, results indicated that while the percentage of extreme family types decreased dramatically from the symptomatic to no-therapy groups (neurotic, 64%; schizophrenic, 56%; therapy, 38%; no therapy, 7%), the percentage of balanced families increased (neurotic, 8%; schizophrenic, 12%; therapy, 38%; no therapy, 48%) (Clark, 1984; cited in Olson, 1986). In a study of chemically dependent and non-chemically dependent families, Olson (1986) found alcoholic families had a significantly higher level of extreme families compared to the non-chemically dependent families.

Further validation came from the investigation of the family systems in sex offenders. Carnes (1985; cited in Olson, 1986) found high levels of extreme family types in both the family of origin (49%) and the current families (66%) of sex offenders; only 19% of the non-offender families were extreme (Carnes, 1985; cited in Olson, 1986). Conversely, low levels of balanced types in family of origin (11%) and current families (19%) of sex-offenders were found; 57% of the non-offender families were balanced (Carnes, 1985; cited in Olson, 1986).

In yet another study, comparisons were made between 58 mother-son dyads from father-absent families. Half of the dyads had an adolescent juvenile offender and the other half had adolescents with no history of arrest or psychiatric referral (Roddick, Henggeler, & Hanson, 1986). Roddick, Henggeler, and Hanson (1986) found that 7% of the delinquents were from balanced families, while 93% were from mid-range or extreme types. Furthermore, 69% of the non-delinquent families were balanced and 31% were mid-range or extreme types (Roddick et al., 1986).

In summary, these validation studies demonstrate the ability of FACES-II and the Circumplex Model to distinguish between symptomatic and non-symptomatic families. Although these studies supported the hypothesis that balanced family types are more functional than extreme family types (Olson, 1986), they fail to provide evidence that given symptoms are specifically linked with a certain type of family system (e.g., alcoholics from extreme family types are not always chaotically enmeshed) (Olson, 1986).

PARENTAL STRESSOR SCALE: PEDIATRIC INTENSIVE CARE UNIT: PSS-PICU

(Miles & Carter, 1983)

Stress theories have put forth an interactive effect involving personal, situational, and environmental factors (Moos & Billings, 1982). As methods were available to measure aspects of parent and situational stressors, Miles and Carter (1983) constructed a tool to measure intensive care unit-related environmental stressors. Miles and Carter (1983) proposed stimuli that may be sources of stress to parents when a child is in a PICU and variables that may interact with these stimuli to affect the overall stress response.

Personal stressors encompass the personal and family characteristics parents bring to the PICU experience, (e.g., age, parental role, educational level, and propensity for anxiety). Situational stressors refer to those variables related to the child and his/her illness, (e.g., perceived severity, type of admission, and adequacy of parental preparation for the experience). Environmental stressors are defined as stress stimuli arising from the physical and psychosocial aspects of the PICU. In an effort to identify parental stress and assist parental coping strategies, Carter and Miles (1983) constructed The Parental Stressor Scale: Pediatric Intensive Care Unit (PSS-PICU). In the absence of standardized norms, the PSS-PICU is used to assess parental stress arising from seven dimensions of the PICU: Child's Behaviour and Emotions, Parental Role Alteration, Sights and Sounds, Child's Appearance, Medical Procedures, Staff Communication, and Staff Behaviours.

In phase 1 of the PSS-PICU's construction, notations were made about particular stressors parents seemed to experience during their child's hospitalization. Parents of

children recently discharged from a PICU were then informally asked to confirm these stressors and identify other aspects of the experience which were perceived as stressful or difficult. From these observations, stressors experienced by parents were identified as personal, situational, and environmental.

One hundred process items defining PICU parental environmental stress were evaluated and examined for conceptual clarity, duplication, clinical relevancy, and level of specificity. The items were then collapsed into 79 items, and categorized into meaningful dimensions of the paediatric intensive care unit environment (Carter & Miles, 1989). Initial dimensions were conceptualized as: Child's Behaviour, Child's Emotional Response, Staff Communication, Staff Behaviour, and Role Deprivation (Carter & Miles, 1989). A 5-point scale was developed to assess parental perceptions of stress level for each item with a zero point to reflect "*not experienced*".

In phase 2, the psychometric properties of the PSS.PICU were evaluated. Forty-eight hours following their child's transfer to the general unit, parents ($n = 165$) of children treated in the PICU for at least 20 hours were asked to retrospectively assess the perceived level of stress produced by the ICU environment (Carter & Miles, 1989).

Internal consistency coefficients of .96 were obtained for the total scale, with dimensional subscale coefficients ranging from .69 to .95 (Carter & Miles, 1983). Item analysis of the 79 items revealed that many subjects responded "*not experienced*" to some of the items assessing Medical Procedures, Child's Behaviour, Staff Communication, and Staff Behaviour (Carter & Miles, 1989). Further examination of the items "*not*

experienced" indicated many were age- and/or case-specific (e.g., rebellion, demanding, and withdrawal not easily evaluated in infants) (Carter & Miles, 1989). Parent elaborations indicated many procedures were rated as *"not experienced"* because they were not witnessed when performed (Carter & Miles, 1989).

To evaluate the PSS:PICU's construct validity, Pearson correlation analyses were performed with scores from the eight dimensions and Spielberger's State Anxiety scores. Correlation coefficients ranging from .27 to .46 ($p < .01$) supported the hypothesis that parental stress occasioned by the ICU environment correlated positively with the level of anxiety generated by the ICU experience (Carter & Miles, 1989).

Principal component factor analysis was performed on the 165 subjects' responses to the 79 items. Initial factor analysis produced 22 factors which explained 75% of the data variance (Carter & Miles, 1989). Following factor analysis, the instrument was revised to include 62-items which conceptually met the following six dimensions of the PICU environment: Sights and Sounds, Medical Procedures, Staff Communication, Child's Behaviour and Emotion, Parental Role Alteration, and Staff Behaviours (Carter & Miles, 1989).

Phase 3 involved administering the 62-item revised PSS:PICU to 510 parents from 5 mid-western intensive care units. Both exploratory and confirmatory factor analyses were performed on the 510 subjects' responses to the 62-item revised instrument. Principal component analyses resulted in a reduction of 62 to 36 items. Seven salient and conceptually clear factors (eigenvalues > 1) emerged, thus adding Child's Appearance as a

seventh dimension of the PSS:PICU (Carter & Miles, 1989).

Following factor analyses, internal consistency of the PSS:PICU was evaluated. An alpha coefficient of .95 was obtained for the total instrument, with seven dimensional subscale coefficients as follows: Child's Appearance, .92; Sights and Sounds, .83; Medical Procedures, .86; Staff Communication, .99; Child's Behaviour and Emotions, .97; Staff Behaviours, .72; and Parental Role Alteration, .99 (Carter & Miles, 1989)

Pearson correlation coefficients were again computed between each of the PSS:PICU dimension scores and State Anxiety scores. Correlation coefficients were: Child's Behaviour and Emotions, .42; Parental Role Alteration, .38; Staff Communication, .31; Medical Procedures, .36; Sights and Sounds, .29; Staff Behaviours, .34; and Child's Appearance, .37 ($p < .0001$) thus supporting the construct validity of the revised instrument (Carter & Miles, 1989).

Initial studies using the PSS:PICU indicated Child's Behaviour and Emotions, and Parental Role Alteration, were the two most stressful aspects of the PICU (Miles, Carter, Riddle, Hennessey, & Eberly, 1989). More specifically, child's pain, altered ability to communicate, and inability to protect and help one's sick child were most stressful to parents. Medical Procedures, Staff Communication, and Child's Appearance were less stressful than Child's Behaviour and Emotions, and Parental Role Alteration, but were more stressful than both Staff Behaviours, and Sights and Sounds (Miles et al., 1989). Further analyses indicated that within the Parental Role Alteration dimension, the following items received the highest stress ratings: being unable to protect my child, and

not knowing how to best help my child (Miles et al., 1989).

Assessment of mother-father perceptions indicated mothers had higher mean scores than fathers on all seven subscale dimensions (Riddle, Hennessey, Eberly, Carter, & Miles, 1989). Within each of the seven dimensions, the following sources of stress were identified: Child's Appearance, tubes in child; Sights and Sounds, sudden sounds of monitor alarms; Medical Procedures, putting needles in my child; Staff Communication, not being sure when I will see doctor; Child's Behaviour and Emotions, acting or looking as if in pain; Staff Behaviours, looking worried about my child; Parental Role Alteration, being unable to protect my child from pain (Riddle et al., 1989).

THE BRIEF SYMPTOM INVENTORY: (BSI) (Derogatis, 1975)

The BSI is 53-item self-report symptom inventory designed to reflect the psychological symptom patterns of psychiatric and medical patients, as well as community non-patient respondents. As a current point-in-time measure of psychological status, the BSI is not a measure of personality. Although the standard time reference for completion of the BSI is "*the past 7 days including today*", evaluations over other specific intervals of time may be made. Usual time for completion requires 8 to 10 minutes, with an additional 2 to 5 minutes for administrative instructions. Typically used with adults, the BSI may also be utilized with adolescents (13 years and above). In addition to adult male and female norms, separate interpretive norms have been developed for adolescents (Derogatis, 1982), the elderly (Hale, Cochran, & Hedgepeth, 1984), and college students (Cochran & Hale, 1985).

Each item of the BSI is rated on a 5-point scale of distress, ranging from "*0 - not at all*" to "*4 - extremely*". It is scored and profiled in terms of 9 primary symptom dimensions, and 3 global indices of distress. Interpretation of the BSI may be done on one of three levels: general measures of psychological status (i.e., 3 global indices) through syndromal representations (i.e., 9 symptom dimensions), to individual symptoms (i.e., 53 items) (Derogatis, 1982).

The 9 primary symptom dimensions are: Somatization, Obsessive-Compulsive, Interpersonal Sensitivity, Depression, Anxiety, Hostility, Phobic Anxiety, Paranoid Ideation, and Psychoticism. Providing psychometric appraisal at a general level of

psychological well-being, the 3 global indices are termed: Global Severity Index (GSI), Positive Symptom Distress Index (PSDI), and Positive Symptom Total (PST).

The **SOMATIZATION** dimension reflects distress arising from perceptions of bodily dysfunction. Components of the definition include: cardiovascular, gastrointestinal and respiratory complaints, gross musculature difficulties, and somatic equivalents of anxiety. The **OBSESSIVE-COMPULSIVE** dimension focuses on thoughts, impulses and actions that are experienced as unrelenting by the individual. **INTERPERSONAL SENSITIVITY** refers to those feelings of personal inadequacy and inferiority, self-deprecation, self-doubt, and discomfort during interpersonal interactions. Symptoms of the **DEPRESSION** dimension include withdrawal from life interest, lack of motivation, hopelessness, and suicidal ideation. The **ANXIETY** dimension is associated with high levels of manifest anxiety, nervousness, tension, panic attacks, apprehension, and feelings of terror. Anger, aggression, irritability, rage, and resentment characterize the **HOSTILITY** dimension. The **PHOBIC ANXIETY** dimension closely resembles the definition of "agoraphobia" and is also termed "phobic anxiety depersonalization syndrome". Primary aspects of the **PARANOID IDEATION** dimension include: hostility, suspiciousness, grandiosity, fear of loss of autonomy, and delusions. The **PSYCHOTICISM** dimension is characterized by feelings of withdrawal, isolation, and schizoid life-style.

Among the indices, the **GLOBAL SEVERITY INDEX** is the most sensitive indicator of an individual's distress, combining information on numbers of symptoms and

intensity. The POSITIVE SYMPTOM DISTRESS INDEX not only provides information on the average level of distress experienced by the individual, it also indicates whether the respondent tends to be a "repressor" or "sensitizer", minimizing or exaggerating distress experiences. The POSITIVE SYMPTOM TOTAL reveals both the extent of the respondent's emotional distress and the number of symptoms the patient reports experiencing.

Alpha coefficients for all 9 dimensions of the BSI ranged from a low of .71 on the Psychoticism dimension to a high of .85 on Depression (Derogatis, 1982). Test-retest reliability coefficients ranged from a low of .68 for Somatization to a high of .91 for Phobic Anxiety (Derogatis, 1982). Coefficients of .90, .87, and .80 were obtained for GSI, PSDI, and PST (Derogatis, 1982). Validation studies between the BSI and clinical scales of the MMPI were $\geq .30$ (Derogatis, 1982).

Screening studies involving patients referred for consultation indicated approximately 80% were identified as psychiatrically positive by the BSI; 87% of these positives were confirmed as cases by subsequent psychiatric diagnosis (Kuhn et al., 1988; cited in Derogatis, 1982). Similarly, the BSI was employed to identify newly diagnosed cancer outpatients who were experiencing psychological distress at time of diagnosis, and would manifest clinical levels of future psychological distress; the BSI correctly identified 84% of those patients who were identified as clinically distressed 1 year following diagnosis (Zabora et al., 1990; cited in Derogatis, 1982). In a study of chronic pain patients, Atkinson, Kremer and Ignelzi (1982) used the BSI to divide the patients into low

and high distressed groups. Atkinson et al (1982) found that high distress pain patients revealed greater mean areas of pain, a greater number of anatomical pain sites, and used a more diffuse pain "language" than did low distress pain patients. The BSI was also used to assess psychological distress in cigarette and alcohol users. Among males in the sample, Somatization, Depression, and Anxiety showed the highest level of discrimination between smokers and non-smokers (Chiles et al., 1990; cited in Derogatis, 1982).

CHILD BEHAVIOUR CHECKLIST: CBCL (Achenbach & Edelbrock, 1983)

Unlike most children's behaviour checklists which limit themselves to the goal of differentiating a clinical from a non-clinical population, Edelbrock and Achenbach (1980) derived a typology of child behaviour profile patterns which differentiated within a clinical population. The CBCL was designed to obtain a systematic report from parents of behaviours observed in their children which may reflect psychological difficulties (Achenbach & Edelbrock, 1983).

The CBCL provides an empirical assessment of symptoms which is based on two large, demographically diverse standardization samples. Children referred and not referred for mental health treatment constitute the 2 standardization samples (Edelbrock & Achenbach, 1980). Achenbach and Edelbrock's (1983) profile types encompass a wide range of behaviour problems, provide a quantitative score of a child's match to a given profile type, and appear to be quite stable. Data is scored and presented as a subscale score, as well as a Total Behaviour Problem score.

The CBCL uses the primary care-giver's responses to a 120-item standardized scale to assess 2 dimensions, Total Behaviour Problems and Social Competence. Total Behaviour Problems are sub-divided into 2 broad-band scales, Internalizing and Externalizing Behaviours. The CBCL has separate age norms for boys and girls: 3-5, 6-11, and 12-18. It has demonstrated a high test-retest reliability, .89, and is a valid discriminator of maladjusted and poorly achieving children (Achenbach & Edelbrock, 1983).

MOTHER-CHILD DYADS (WPPSI Block Design Subtest)

As an additional indicator of family functioning, mother-child interaction style was evaluated using the WPPSI Block Design Subtest. As determined by the child's age, mother and child were given one easy and one difficult design to complete. A 10-minute time limit was given in which to complete each design. The task was completed by 3 to 5 year old siblings of children who had been hospitalized in the hospital's PCCU. Maternal and child behaviours and verbalizations were manually and audio-recorded by an observer.

Mother-child dyad tasks such as this have been employed in previous research involving parent-child interaction style. In an assessment of the IQ test performance of traditionally and transracially adopted black children, Moore (1986) found transracially adopted black children's responses to test demands were more assertive. Transracially adopted black children also showed more confidence in themselves as problem solvers and a willingness to attempt a solution to a challenging demand, even at the risk of being incorrect (Moore, 1986). Moore concluded (1986) the differences in children's response styles may be attributable to differences between black and white adoptive mothers in their affective and teaching behaviours. White adoptive mothers tended to elicit more positive affect and encouragement than black adoptive mothers who tended to be less supportive of child-initiated strategies that did not contribute to the problem's solution (Moore, 1986). Black adoptive mothers' attitudes may have taught their children that rather than guess at a challenging question's answer and risk adults' disapproval, it is better to request help (Moore, 1986).

Parent-child interactions have also been examined within the context of ordinal position and home observations. Oldest children have been described as more independent, dominant, self-sufficient, high in achievement and leadership, and more attention-seeking with adults; later-born children have been described as popular with peers, and as being non-conforming (Baskett, 1984). Others have also indicated that mothers respond differently to their first-born children than they do to their later-born children (Dunn & Kendrick, 1979; cited in Baskett, 1984).

As differential treatment by parents or differences in behaviour by siblings could be more a result of age of the target child than of birth order, Baskett (1984) sought to examine the parent-child interactions of children of similar age but different birth-order positions. Baskett (1984) found first-born children showed a greater preference for interacting with parents; last-born children tended to divide their interactions more evenly between parents and older siblings. While first and last-born children received approximately equal levels of positive responses from other family members, Baskett (1984) found first-born children were more likely to receive negative responses from family members than were last-born children of the same age (Baskett, 1984).

PEABODY PICTURE VOCABULARY TEST-REVISED; PPVT-R (Dunn & Dunn, 1981)

The PPVT-R is an individually administered, norm-referenced, test of hearing vocabulary, designed for persons 2.5 through 40 years of age. The Peabody furnishes a measure of receptive oral vocabulary and basic cognitive functioning (Dunn & Dunn, 1981). The PPVT-R consists of a series of 175 plates, each containing four pictures. As each plate is presented, the examiner provides a stimulus word orally; the test taker responds by pointing to or in some way designating which picture on the plate best illustrates the meaning of the stimulus word. Each individual begins with the plate corresponding to his/her chronological age.

Following testing, which requires 10-20 minutes, raw scores are converted to standard scores, percentile ranks, and stanines. The PPVT-R possesses an internal consistency reliability of .81, a test-retest reliability of .82, and a criterion validity of .70 (Dunn & Dunn, 1981). Although the PPVT-R has been published too recently to permit a significant accumulation of direct validity data, a survey of over 300 studies using the PPVT yielded high correlations with other vocabulary tests, moderate correlations with tests of verbal intelligence and scholastic aptitude, and promising relations with performance on educational achievement tests (Dunn & Dunn, 1981).

FACES II

For each of the following items, please indicate how well it describes your family. Choose the appropriate number on the scale at the top of the page and write it in the blank to the left of the item.

Answer Scale:

1	2	3	4	5
Almost Never	Once in A while	Sometimes	Frequently	Almost Always

-
- ___ 1. Family members are supportive of each other during difficult times.
 - ___ 2. In our family, it is easy for everyone to express his/her opinion.
 - ___ 3. It is easier to discuss problems with people outside the family than with other family members.
 - ___ 4. Each family member has input in major family decisions.
 - ___ 5. Our family gathers together in the same room.
 - ___ 6. Children have a say in their discipline.
 - ___ 7. Our family does things together.
 - ___ 8. Family members discuss problems and feel good about the solutions.
 - ___ 9. In our family, everyone goes his/her own way.
 - ___ 10. We shift household responsibilities from person to person.
 - ___ 11. Family members know each other's close friends.
 - ___ 12. It is hard to know what the rules are in our family.
 - ___ 13. Family members consult other family members on their decisions.
 - ___ 14. Family members say what they want.
 - ___ 15. We have difficulty thinking of things to do as a family.
 - ___ 16. In solving problems, the children's suggestions are followed.
 - ___ 17. Family members feel very close to each other.
 - ___ 18. Discipline is fair in our family.
 - ___ 19. Family members feel closer to people outside the family than to other family members.
 - ___ 20. Our family tries new ways of dealing with problems.
 - ___ 21. Family members go along with what the family decides to do.
 - ___ 22. In our family, everyone shares responsibilities.
 - ___ 23. Family members like to spend their free time with each other.
 - ___ 24. It is difficult to get a rule changed in our family.
 - ___ 25. Family members avoid each other at home.
 - ___ 26. When problems arise, we compromise.
 - ___ 27. We approve of each other's friends.
 - ___ 28. Family members are afraid to say what is on their minds.
 - ___ 29. Family members pair up rather than do things as a total family.
 - ___ 30. Family members share interests and hobbies with each others.

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APPENDIX C- Parental Stressor Scale: Pediatric ICU (pg. 82)

APPENDIX D- BSI (pg. 86)

APPENDIX E- Child Behavior Checklist For Ages 4-18 (pg. 88)

Appendix F

Coding Scheme: Mother-Child Interaction Task (Rosen & D'Andrade, 1959)

BEHAVIOUR	DEFINITION	RELIABILITY
MATERNAL		
Approval	Expresses approval, gives love, comfort, positive acts that involve reactions to the child and only indirectly the child's performance	.96
Hostility	Expresses hostility, denigrates, makes sarcastic remarks, negative affective reactions to the child, and only indirectly the child's performance	.94
Positive Tension	Jokes, laughs, grins, behaviours focused toward child, but are diffused, undirected reactions to the situation	.92
Negative Tension	Shows irritation, scowls, coughs, behaviours not focused toward child, but are diffused, undirected reactions toward the situation in general	.94
Positive Evaluation	Gives explicit positive evaluation of child's performance, indicates job well done	.92
Negative Evaluation	Gives explicit negative evaluation of child's performance, indicates job poorly done	.93
Enthusiasm	Attempts to push up performance through enthusiasm, urges, cheers	.90
Displeasure	Attempts to push up performance through displeasure, urges on indicating disappointment at speed and level of performance	.92
Instructs, Nonspecific	Gives nonspecific directions, gives hints, clues, general instructions about how to solve the task	.94
Instructs, Specific	Gives specific instruction, detailed specific information about how to do the task	.96

Coding Scheme: Mother-Child Interaction Task, contd.

BEHAVIOUR	DEFINITION	RELIABILITY
CHILD		
Requests Aid	Asks for help, advice, or information	.94
Rejects Aid	Rejects help, advice, or information	.93
Positive Tension	Jokes, laughs, grins, behaviours focused toward mother, but are diffused, undirected reactions to the situation	.98
Negative Tension	Shows, irritation, scowls, coughs, behaviours not focused toward mother, but are diffused, undirected reactions toward the situation in general	.91

Appendix G

PARENT-RESEARCHER INTERVIEW: GROUP 1

COMPONENT #1: I would like to begin by talking about the time your child spent in the Pædiatric Critical Care Unit (PCCU) and what you knew about your child's illness. Can you tell me what was wrong with your child (i.e., medical diagnosis), and what you understood would happen to your child as his/her illness advanced?

COMPONENT #2: As you look back on the time your child was in the PCCU, how good do you think the communication was between you and the health care team?

COMPONENT #3: On _____ day, you met with the health care team to discuss your child's illness and possible future outcomes. During this meeting, you also discussed the possibilities of withdrawing your child's life-support or continuing treatment. Can you tell me what you remember about that day and the meeting, itself?

What was important to you in making your decision?

Did you feel the decision you made was your own, or did you feel pressured into this decision? (If parents did not make decision), who made the decision and how was it made?

Given the decision that was made, how did the subject come up and do you feel you were ready for it?

Please describe to me how you and your spouse normally decide upon important matters.

During the time your child was in hospital, did you feel that you and your spouse shared the same points of view concerning your child's care, or did you disagree about the ultimate decision?

Do you feel that the way you and your spouse make decisions now has changed as a result of your child's hospital stay?

COMPONENT #4: Your child passed away in the PCCU. Can you tell me what happened when your child died?

Looking back on it now, is there anything else you wish had been done, or wish that could have been done?

"Decision-Making Procedures in the PCCU"

Subject #: _____

PARTICIPANTS IN GROUP #1 INTERVIEW: Parents of children who died in the PCCU following a parent-physician discussion to forgo life-sustaining measures.

OPENING OF INTERVIEW - THANKING PARENTS FOR PARTICIPATION:

Mr. & Mrs. _____, before we begin the interview I would like to thank you for taking the time to participate in this study.

Our goal is to look at your thoughts and feelings around the time your son/daughter was in the Paediatric Critical Care Unit at the Children's Hospital of Western Ontario/London Health Sciences Centre.

Talking with me at this time about your child's hospital stay may cause you or your family to feel sad or upset as you re-live or remember that time. That was a very difficult time for you, and I do not want you to feel embarrassed or uncomfortable by any feelings you may have.

If you do feel upset at any time during the interview, please take as much time as you need to answer. If you feel you cannot answer a question, please let me know and we will go on to the next question.

Do you have any questions or concerns that I can answer before we begin? If you're ready then, let's start...

BEGINNING THE INTERVIEW:

1. Collection of Demographic Data:
2. Collect questionnaires from parents that were mailed to them

COMPONENT #1: UNDERSTANDING OF CHILD'S MEDICAL CONDITION

I WOULD LIKE TO BEGIN BY TALKING TO YOU ABOUT THE TIME YOUR CHILD SPENT IN THE PÆDIATRIC CRITICAL CARE UNIT (PCCU) AND WHAT YOU KNEW ABOUT YOUR CHILD'S ILLNESS.

CAN YOU TELL ME WHAT WAS WRONG WITH YOUR CHILD (i.e., MEDICAL DIAGNOSIS), AND WHAT YOU UNDERSTOOD WOULD HAPPEN TO YOUR CHILD AS HIS/HER ILLNESS/DISEASE ADVANCED?

The following is a list of prompts which may be used by the Research Assistant to elicit further information from parents regarding their understanding of their child's medical condition. Prompts will only be used after the above question has been answered, if relevant to the child's particular situation, and/or if initially brought up by parents in course of the interview.

PROMPTS:

- 1) EXPECTATION OF CHILD'S DEATH WITH THE GIVEN DIAGNOSIS
 - a) if death expected, when did parents expect this to occur?
- 2) CHILD'S DEPENDENCE ON MEDICAL-TECHNOLOGY; HAD DOCTORS OR NURSES BROUGHT UP THE...
 - a) possibility of a tracheostomy
 - b) possibility of artificial feeding through a tube in the nose or stomach
 - c) possibility of child surviving if kept on breathing machine for all or part of day

**** If any of the above possibilities are mentioned to or by parents, parents will be asked to comment on the following:**

- d) what type of life did they feel this would mean for their child?
 - e) at the time, how did they feel about the acceptability of these procedures e.g., some parents have said they decided against a tracheostomy because this prevented their child from talking, whereas others have said at least a tracheostomy meant their child was alive. How did they feel about the choices that were given to them?
- 3) CHILD'S AMBULATORY ABILITIES; HAD DOCTORS OR NURSES DISCUSSED THE...
 - a) possibility of child ever walking or talking
 - b) possibility of child going to school
 - c) possibility of child existing in a wheelchair
 - 4) CHILD'S FUTURE FUNCTIONING
 - a) what did parents understand their child would be able to do in the future?

UNDERSTANDING

SCALE #1: a) Returning now to your child's medical situation, how would you rate your understanding of your child's condition/illness?

1	2	3	4	5
did not understand	somewhat unclear	middle	fairly well	understood very well

SCALE #2: a) At the time, how sure did you feel about the future of your child's health?

b) How sure did you feel the doctors were about the future of your child's health?

1	2	3	4	5
not sure at all	somewhat unsure	middle	fairly sure	very sure

SCALE #3: a) Thinking back to some of the procedures that may have been suggested to you (e.g., tracheostomy), how would you rate your acceptability of those procedures?

1	2	3	4	5
completely unacceptable	somewhat unacceptable	middle	fairly acceptable	completely acceptable

SCALE #4: a) At the time, how well did you feel you understood the possible outcomes of your child's health/future?

b) How well did you feel that you understood your decision could change as your child's condition changed?

1	2	3	4	5
not well at all	not very well	middle	fairly well	very well

COMPONENT #2: COMMUNICATION WITH HEALTH CARE STAFF

**AS YOU LOOK BACK ON THE TIME YOUR CHILD WAS IN THE PCCU,
HOW GOOD DO YOU THINK THE COMMUNICATION WAS BETWEEN YOU
AND THE HEALTH CARE STAFF?**

PROMPTS:

- 1) **AVAILABILITY OF HEALTH CARE TEAM MEMBERS**
 - a) did parents find the doctors were available to them?
 - b) did parents find the nurses were available and helpful?
 - c) were there other caregivers, such as respiratory therapists, social workers, or pastoral care workers that you found helpful at this time?
 - d) did parents find specific individuals unhelpful?
 - e) can parents remember the name of their child's attending physician or the name of their child's primary nurse?
 - f) did parents find, on the whole, there was too many people or too few people to help during this time?
- 2) **AMOUNT OF INFORMATION GIVEN TO PARENTS**
 - a) was the amount of information the doctors provided you enough?
 - b) did the nurses provide you with enough information?

COMMUNICATION**SCALE #1:** a) How would you rate the communication between you and the doctors?

b) How would you rate the communication between you and the nurses?

1	2	3	4	5
very poor	somewhat poor	middle	fairly good	excellent

SCALE #2: a) How would you rate the amount of information given to you by the doctors concerning your child's treatment and the possible outcomes?

b) How would you rate the amount of information given to you by the nurses concerning your child's treatment and the possible outcomes?

1	2	3	4	5
not enough	too little	middle	almost enough	plenty

SCALE #3: a) How clear was the information the doctors gave you?

b) How clear was the information the nurses gave you?

1	2	3	4	5
not clear at all	somewhat unclear	middle	fairly clear	very clear

SCALE #4: a) How would you rate the availability of the doctors to you?

b) How would you rate the availability of the nurses to you?

1	2	3	4	5
never available	somewhat unavailable	middle	fairly available	always available

COMPONENT #3: CONTROL OVER DECISIONS/TREATMENT

ON _____ DAY, YOU MET WITH THE HEALTH CARE TEAM TO DISCUSS YOUR CHILD'S ILLNESS AND POSSIBLE FUTURE OUTCOMES. DURING THIS MEETING, YOU ALSO DISCUSSED THE POSSIBILITIES OF WITHDRAWING YOUR CHILD'S LIFE-SUPPORT OR CONTINUING TREATMENT.

CAN YOU TELL ME WHAT YOU REMEMBER ABOUT THAT DAY AND THE MEETING, ITSELF?

PROMPTS:

- 1) CHILD'S MEDICAL CONDITION AND MEDICAL CHOICE TO BE MADE
 - a) at that meeting, the doctors were discussing with parents the possibility of withholding or withdrawing one of the following: dialysis, vasoactive drugs, CPR.
- 2) SPECIFICS OF DAY AND MEETING
 - a) time and place of discussion
 - b) people present
 - c) who initiated discussion?
- 3) UNDERSTANDING OF DECISION TO BE MADE
 - a) did parents understand that a decision was being made regarding the care of their child?
 - b) did parents understand they were being asked to make that decision concerning their child's treatment/care?

IF YES TO 3B), WHAT WAS IMPORTANT TO YOU IN MAKING YOUR DECISION?

PROMPTS:

- 1) FACTORS INFLUENCING DECISION
 - a) who brought up the idea (i.e., doctors initiated subject)
 - b) quality of life of their child
 - c) impact on family
 - d) financial concerns
 - e) spiritual beliefs
 - f) any other factors that parents remember
- 2) FLEXIBILITY OF DECISION
 - a) did parents understand that they could change their decision if their child's medical situation changed?

DID YOU FEEL THE DECISION YOU MADE WAS YOUR OWN, OR DID YOU FEEL PRESSURED INTO THIS DECISION?

PROMPTS:

1) **CONTROL OVER DECISION**

- a) did parents feel decision was theirs to make, or was it felt nurses/doctors made the decision for their child?

2) **TIMELINESS OF INFORMATION GIVEN TO PARENTS**

- a) did parents feel that the discussions around their child's diagnosis and possible outcome were initiated at the right time or were they too soon or too late with respect to their child's admission to the unit or medical condition?

3) **TIME TO MAKE DECISION**

- a) did parents feel they had enough time to make their decision (i.e., hours, days, weeks)?
- b) how much time did you have to make the decision?

4) **EXPRESSION OF FEELINGS**

- a) did parents feel they had enough opportunity to express their thoughts and feelings?
- b) did parents feel doctors understood the thoughts/feelings?

5) **FEELINGS TOWARD DISCUSSION ITSELF**

- a) what are parents feelings towards the discussion and the decision they ultimately made?

6) **PRESENT COMFORT WITH DECISION**

- a) do parents now feel comfortable with the decision or do they regret certain things about the discussion and the decision-making process in the PCCU?

IF NO TO 3B), WHO MADE THE DECISION AND HOW WAS IT MADE?

PROMPTS:

1) **EXPRESSION OF FEELINGS**

- a) did parents feel they did not have enough time to express their thoughts/feelings?
- b) did parents feel the doctors did not understand their thoughts/feelings?

2) **COMFORT WITH DECISION**

- a) given the decision that was made, how do parents now feel about the decision; do they regret certain things about the discussion or the decision-making process?

GIVEN THE DECISION THAT WAS MADE, HOW DID THE SUBJECT COME UP AND DO YOU FEEL YOU WERE READY FOR IT?

PROMPTS:

- 1) INITIATOR OF DISCUSSION
- 2) EXPECTATION OF DISCUSSION
 - a) were parents surprised by this discussion, or had they been expecting it?
 - ** If expected**, had you and your spouse discussed it between yourselves earlier?
 - ** If surprised**, was that because you were not given enough information about your child's medical situation? Could anything have been done to prepare you?
- 3) PRESENT FEELINGS TOWARD HEALTH CARE SYSTEM
 - a) Do you think your feelings about doctors, nurses, and hospitals changed at all around the time of the discussion we are talking about? If so, how?

PLEASE DESCRIBE TO ME HOW YOU AND YOUR SPOUSE NORMALLY DECIDE UPON IMPORTANT MATTERS.

PROMPTS:

- 1) PRIOR DECISION-MAKING (e.g.) buying home/car, school child should attend

DURING THE TIME YOUR CHILD WAS IN HOSPITAL, DID YOU FEEL THAT YOU AND YOUR SPOUSE SHARED THE SAME POINTS OF VIEW, OR DID YOU DISAGREE ABOUT THE ULTIMATE DECISION?

PROMPTS:

- 1) DID ANYONE PLAY A ROLE IN THE DECISION-MAKING PROCESS BESIDES THE PARENTS AND THE HEALTH CARE TEAM?
 - a) extended family
 - b) other staff
 - c) community e.g., clergy
 - d) are these people the same people who would normally help parents?

DO YOU FEEL THAT THE WAY YOU AND YOUR SPOUSE MAKE DECISIONS NOW HAS CHANGED AS A RESULT OF YOUR CHILD'S HOSPITAL STAY?

PROMPTS:

- 1) DID CHILD'S HOSPITAL STAY AFFECT HOW FAMILY PRESENTLY FUNCTIONS?

CONTROL

SCALE #1: a) How well do you feel you understood that a decision was being made regarding the care of your child?

b) How well do you feel you understood that you were being asked to make the decision concerning your child's future treatment?

c) How well do you feel you understood that your decision was flexible i.e., your decision could change and another decision made if child's medical condition changed?

1	2	3	4	5
completely misunderstood	somewhat misunderstood	middle	fairly well understood	completely understood

SCALE #2: a) How do you feel now about the way in which the discussion around your child's treatment was carried out?

b) How do you feel about the adequacy of the information given to you at that time?

c) How do you feel about the amount of support you were given during that time?

d) How do you feel now about the overall decision-making process in the PCCU?

1	2	3	4	5
very badly	somewhat badly	middle	fairly well	very good

SCALE #3: a) At the time, how much control did you feel you had over the decision you were being asked to make?

b) At the time, did you feel you had enough time to express your feelings and thoughts?

c) Do you feel you had enough time to make the decision you were being asked to make?

1	2	3	4	5
not enough	could have had more	middle	a fair amount	more than enough

CONTROL - CONTD

SCALE #4: a) Was the outcome of your decision what you expected it to be?

1 not expected at all	2 not exactly what was expected	3 middle middle	4 almost what was expected	5 exactly what was expected
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SCALE #5: a) At the time the subject concerning your child's treatment was brought up, did you feel you were ready to have the subject brought up?

1 completely surprised	2 somewhat surprised	3 middle	4 fairly expected	5 completely expected
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SCALE #6: a) When the subject was raised, did you feel ready to discuss those issues?

1 not ready at all	2 somewhat unready	3 middle	4 fairly ready	5 very ready
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SCALE #7: a) How do you feel your child's hospital stay has affected the way you feel about doctors, nurses, and hospitals?

b) How has your child's hospital stay affected the way your family now makes decisions?

c) How has your child's hospital stay affected the way your family presently functions?

1 not at all	2 very little	3 middle	4 a fair bit	5 a great deal
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SCALE #8: a) How supportive was the staff while you were making your decision?

b) How supportive was your extended family?

c) How supportive were other people in the community?

1 not supportive at all	2 somewhat unsupportive	3 middle	4 fairly supportive	5 very supportive
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COMPONENT #4: COMFORT WITH DECISION

YOUR CHILD PASSED AWAY IN THE PCCU. CAN YOU TELL ME WHAT HAPPENED WHEN YOUR CHILD DIED?

PROMPTS:

- 1) DID PARENTS FIND THE STAFF HELPFUL IN DEALING WITH THEIR SADNESS?
- 2) DID THEY OFFER PARENTS THE OPPORTUNITY TO HOLD THEIR SON/DAUGHTER WHEN HE/SHE PASSED AWAY?
- 3) DID THEY TRY AND GIVE PARENTS A QUIET AREA TO BE WITH THEIR SON/DAUGHTER?
- 4) DID THEY RESPECT THEIR PREFERENCES AS A FAMILY AND ALLOW OTHERS, SUCH AS GRANDPARENTS, ACCESS?
- 5) WERE PARENTS TOLD ABOUT ANY SUPPORT SYSTEMS THAT MIGHT BE AVAILABLE TO HELP THEM DURING THEIR GRIEVING PROCESS, SUCH AS BEREAVED FAMILIES, SOCIAL WORK SERVICES, PASTORAL CARE SERVICES, ETC.?
- 6) WERE PARENTS TOLD ABOUT THE ORGAN DONATION PROCESS?

LOOKING BACK ON IT NOW, IS THERE ANYTHING ELSE YOU WISH HAD BEEN DONE, OR WISH THAT YOU COULD HAVE DONE?

COMFORT

SCALE #1: a) How would you rate the staff's ability to help you with your sadness?

1	2	3	4	5
not helpful at all	somewhat unhelpful	middle	fairly helpful	very helpful

SCALE #2: a) How would you rate the hospital's current discussion procedures concerning removing or continuing treatment?

1	2	3	4	5
very poor	somewhat poor	middle	fairly good	very good

SCALE #3: a) How accepting are you now of the processes (circumstances) around your child's death?

1	2	3	4	5
very uncomfortable	somewhat uncomfortable	middle	fairly comfortable	very comfortable

SCALE #4: a) How would you rate the staff's ability to respect your preferences as a family at the time of your child's death?

b) How would you rate the amount of information about available support systems that was given to you?

1	2	3	4	5
very poor	somewhat poor	middle	fairly good	very good

CONCLUSION OF INTERVIEW:

I realize this interview must have been difficult for you. I appreciate your courage, your openness, and the time you have given to participate in this study.

I have come to the end of my interview. Are there any particular concerns or anything you feel I have missed during the course of our discussion that was important to you and/or your spouse in reaching the ultimate decisions you made?

I also want to assure you that I have been told by Dr. Frewen and the hospital staff that they are very willing to meet with you again to discuss any matters of concern that you might have with respect to the hospital stay and your son/daughter's illness and health care. I would also like to tell you that the hospital's psychologists will meet with you if you feel you are having difficulties coping with any part of the care your child received or decisions that were made concerning your child.

Thank you most sincerely for consenting to participate in this study and ultimately, we believe, helping the doctors and nurses in the Paediatric Critical Care Unit provide better care for future children and their families.

Appendix H

PARENT-RESEARCHER INTERVIEW:

GROUP 2 (CHILD DIED WITHOUT OCCURRENCE OF A DNR DISCUSSION)

COMPONENT #1: I would like to begin by talking about the time your child spent in the Pædiatric Critical Care Unit (PCCU) and what you knew about your child's illness. Can you tell me what was wrong with your child (i.e., medical diagnosis), and what you understood would happen to your child as his/her illness advanced?

COMPONENT #2: As you look back on the time your child was in the PCCU, how good do you think the communication was between you and the health care team?

COMPONENT #3: Did you feel that you had any control over the treatment and care your child was receiving, or did you feel that the doctors and nurses were in control?

Please describe to me how you and your spouse normally decide upon important matters.

During the time your child was in hospital, did you feel that you and your spouse shared the same points of view concerning your child's care, or did you disagree about the ultimate decision?

Do you feel that the way you and your spouse make decisions now has changed as a result of your child's hospital stay?

COMPONENT #4: Your child passed away in the PCCU. Can you tell me what happened when your child died?

Looking back on it now, is there anything else you wish had been done, or wish that could have been done?

Appendix I

PARENT-RESEARCHER INTERVIEW:
GROUP 3 (CHILD SURVIVED HIS/HER CRITICAL ILLNESS)

COMPONENT #1: I would like to begin by talking about the time your child spent in the Pædiatric Critical Care Unit (PCCU) and what you knew about your child's illness. Can you tell me what was wrong with your child (i.e., medical diagnosis), and what you understood would happen to your child as his/her illness advanced?

COMPONENT #2: As you look back on the time your child was in the PCCU, how good do you think the communication was between you and the health care team?

COMPONENT #3: Did you feel that you had any control over the treatment and care your child received, or did you feel that the nurses and doctors were in control?

Please describe to me how you and your spouse normally decide upon important matters.

During the time your child was in hospital, did you feel that you and your spouse shared the same points of view concerning your child's care, or did you disagree about the ultimate decision?

Do you feel that the way you and your spouse make decisions now has changed as a result of your child's hospital stay?

COMPONENT #4: Looking back on now on the time your child spent in the PCCU, is there anything else you wish had been done, or wish that could have been done?

Appendix J

LETTER OF INFORMATION TO PARENTS

Dear Parent:

**RE: DECISION-MAKING PROCEDURES
IN THE PÆDIATRIC CRITICAL CARE UNIT**

I understand you have recently been contacted by one of the doctors at the Children's Hospital of Western Ontario/London Health Sciences Centre concerning your possible involvement in a study entitled "Decision-Making Procedures in the Pædiatric Critical Care Unit". In this study we are attempting to examine the feelings and thoughts of parents, brothers, and sisters about the care your child received during his/her hospital stay. Specifically, we are hoping to talk to you and your spouse about your child's hospital stay. If possible, we would also like to meet with any other children you may have who are now between 3 and 5 years old. We want to know your thoughts about the doctors, nurses and other staff you came into contact with and whether you found the information they provided helpful or not helpful, as you tried to deal with your child's serious illness. We believe that you as parents are the best judges of whether or not we effectively provided you and your spouse with appropriate and timely information in order to make the difficult decisions during your child's intensive care stay.

We understand that participation in this study may cause both you and your spouse and possibly even your family, to experience feelings of sadness as you think back to those difficult hours and days. Nevertheless, we believe seeking out this information is important if we are going to help future families cope with these very difficult and personal decisions.

The study will involve you and/or your spouse meeting with a research assistant (*Elizabeth Votta*) and answering a series of questions. These questions will require you to think back specifically to those difficult days in the intensive care unit when your child was very ill. We want to look at your understanding of your child's medical condition and the factors that you felt were personally important in making the decisions you eventually did with respect to his/her care. We also want to ask you questions about the things you found helpful and not helpful during your child's hospital stay and the things that later helped you cope with those difficult memories and feelings. Finally, we will be asking you to complete some brief questionnaires which explore your current feelings and ask you about the impact of the decisions you made upon both yourselves, your marital relationships, and specifically, on any other children you may have who are now between 3 and 5 years old.

Participation in the study is voluntary. You may refuse to participate or withdraw from the study at any time without penalty. We expect the interview itself will last up to 2 hours. If you agree to participate we will mail you a package of questionnaires to fill out before we meet. You may refuse to answer any questions during the interview or when filling in the questionnaires. These questionnaires should take about 30 minutes to 1 hour to complete and will look at the following areas:

1. Family Functioning - this questionnaire rates how your child's medical condition influenced your family, and how family members get along and adjust in times of difficulty.
2. Parent Stressor Scale: Paediatric Intensive Care Unit - this questionnaire rates how stressful you felt various aspect of the PICU environment were to you.
3. System Inventory - this questionnaire evaluates what your feelings toward the time your child was in the PCCU, both before and after the interview.
4. Child Behaviour and Adjustment - this questionnaire is concerned with the behaviours of any other children you may have who are between the ages of 3 and 5 years. We are asking you to complete this questionnaire to help us better understand what effects your child's illness and hospital stay may have had on their behaviour and adjustment.
5. Picture Vocabulary Test/Parent-Child Puzzle Task - to further understand how your child's hospital stay may have affected your other child's behaviour, we would also like him/her to complete a picture-vocabulary test, and then with your help, to do a short puzzle.

As part of this study, we will also be asking the doctor, primary nurse, and respiratory therapist directly involved in your child's care to complete a questionnaire. This questionnaire will contain questions about the health care team's understanding of your child's medical situation, and how they thought you were feeling about and understanding your child's medical condition.

We would like, with your permission, to record our interview with you so that we may ensure all of the information is collected correctly. All of your answers will be kept strictly private. We will also be happy to provide you and/or your spouse with a copy of the tape, as well as the results of any questionnaires you will have completed. We also intend to provide you with a copy of the results of our study when it is completed. We will pick up the completed questionnaires at the interview.

I do hope this information will help prepare you for my telephone call to your home regarding your possible participation in this study. In thinking about what your participation will involve, please understand that you do not have to participate in all parts of the study. For example, you may choose to complete the interview and the questionnaires, but not complete the puzzle task with your child. We will be grateful for any information you will feel comfortable providing to us. We would also like you to know that the hospital staff and the hospital psychologists will meet with you if you feel you are having difficulties coping with any part of the care your child received or with the decisions that were made concerning your child.

If you have any further immediate questions, I (Elizabeth Votta) or your doctor would be happy to answer these. We can be reached at 519-685-8137 or my home, (Elizabeth) 519-642-1264. In any event, I will be calling your home within the next week to discuss your involvement. If you decide to participate, I want to assure you that I would be more than happy to travel to your home to conduct the interview at a convenient time to you and your spouse. Thank you for taking the time to talk with the doctor on the telephone and read this letter. I look forward to talking to you again in the near future.

Sincerely,

Elizabeth Votta
B.A. Honours Psychology

Dr. Tim Frewen
Vice-President Medical & Dental Affairs / Associate Professor, Paediatrics
Children's Hospital of Western Ontario/London Health Sciences Centre

Dr. Beth Mitchell
Director of Paediatric Psychology / Manager, Mental Health Care / Associate Professor
Children's Hospital of Western Ontario/London Health Sciences Centre

Dr. Dalice Sim
Clinical Bioethicist, Paediatric Critical Care Unit
Children's Hospital of Western Ontario/London Health Sciences Centre

Dr. Bryan Magwood
Pædiatric Critical Care Unit,
Children's Hospital of Western Ontario/London Health Sciences Centre

Ms. Monica Green, R.N.,
Pædiatric Critical Care Unit,
Children's Hospital of Western Ontario/London Health Sciences Centre

Dr. Cathy Maan
Pædiatric Psychology,
Children's Hospital of Western Ontario/London Health Sciences Centre

Appendix K

CONSENT FORM

I have read the letter of information regarding the research project, "Decision-Making Procedures in the Pædiatric Critical Care Unit". I have had the chance to discuss all important questions and concerns with the research assistant.

I hereby consent to the participation of my child and my family in this project.

Parent(s) / Guardian(s) Signature

Sibling's Signature

Witness (Research Assistant.)

Date

Appendix L

DEMOGRAPHIC INFORMATION COLLECTION SHEET

SUBJECT #: _____ PIN #: _____ DATE: ____/____/____

PARENTS' NAMES _____

CHILD'S NAME _____

Sex: M F CHILD'S DATE OF BIRTH: ____/____/____

{ IF APPLICABLE: } DATE OF CHILD'S DEATH: ____/____/____

{ IF APPLICABLE: } AGE AT TIME OF DEATH: _____

CHILD'S ATTENDING PHYSICIAN: _____

CHILD'S PRIMARY DIAGNOSIS: _____

DATE OF FIRST ADMISSION TO PCCU: ____/____/____

LENGTH OF TIME SPENT IN PCCU: _____

CHILD'S RACE:	1. WHITE _____	2. BLACK _____
	3. HISPANIC _____	4. ASIAN _____
	5. NATIVE CANADIAN _____	6. OTHER _____

CHILD'S RESIDENCE:	1. HOME (TWO PARENTS) _____
	2. HOME (MOTHER ONLY) _____
	3. HOME (FATHER ONLY) _____
	4. FOSTER HOME _____
	5. GROUP HOME _____
	6. OTHER _____

NUMBER OF OTHER CHILDREN AT HOME: _____

1. NAME _____ AGE _____ SEX M F

2. NAME _____ AGE _____ SEX M F

3. NAME _____ AGE _____ SEX M F

MOTHER'S DATE OF BIRTH ____ / ____ / ____ AGE _____

FATHER'S DATE OF BIRTH ____ / ____ / ____ AGE _____

EDUCATION:

1. GRADE 1 - 8
2. GRADE 9 - 12
3. GRADE 13
4. SOME COLLEGE/UNIVERSITY
5. COLLEGE/UNIVERSITY GRAD
6. MASTERS
7. DOCTORATE
8. VOCATIONAL/TECHNICAL

MOTHER FATHER

_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____

MARITAL STATUS:

1. MARRIED
2. SEPARATED
3. DIVORCED
4. SINGLE
5. COMMON LAW
6. OTHER

MOTHER FATHER

_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____

MOTHER'S OCCUPATION: _____

FATHER'S OCCUPATION: _____

EMPLOYMENT STATUS:

1. FULL-TIME
2. PART-TIME
3. STUDENT
4. UNEMPLOYED
5. NEVER EMPLOYED

MOTHER FATHER

_____	_____
_____	_____
_____	_____
_____	_____
_____	_____



