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Maternal distress and perceptions of infant development following extracorporeal membrane oxygenation and conventional ventilation for persistent pulmonary hypertension

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Summary

Neurodevelopmental outcome and concurrent maternal distress were examined for infants who suffered persistent pulmonary hypertension at birth and were treated with either extracorporeal membrane oxygenation (ECMO) ($n = 19$) or conventional ventilation (CV) ($n = 15$). Mothers were asked to complete inventories assessing their infant's (mean age 8.74 months) developmental growth as well as their own psychological health. Relevant sociodemographic and treatment parameters were also entered into the analysis. The results indicated that ECMO and CV infants did not differ on developmental indices and impairment rates were 15–23% respectively, similar to previous reports. In addition, ECMO and CV mothers did not differ in their reports of psychological distress. Correlational analyses revealed that length of treatment for ECMO but not CV infants significantly predicted developmental delay and maternal distress. For CV mothers, maternal distress was associated with the perception of delayed language. The results are discussed in terms of the limited morbidity associated with ECMO and CV interventions and the possible role of a 'vulnerable child syndrome' in understanding the maternal–infant relationship following ECMO therapy.

Keywords: maternal distress, pulmonary hypertension

Child: care, health and development

VOLUME 21
NUMBER 1

1995

PAGES 53–65

Introduction

Extracorporeal membrane oxygenation (ECMO) provides cardiopulmonary support for full-term or near-term infants with severe cardiac and respiratory failure refractory to conventional medical management (Bartlett *et al.* 1982). ECMO utilizes an extracorporeal perfusion circuit with an artificial lung to provide gas exchange and assisted circulation for neonates suffering respiratory failure, most often due to persistent pulmonary hypertension (PPHN) (Fox & Duara 1983). As ECMO involves the use of systemic anticoagulation and the surgical cannulation of the right common carotid artery and jugular vein, serious morbidity risks are associated with the procedure (Ment *et al.* 1966; Cilley *et al.* 1986; Hansen *et al.* 1986; Glass *et al.* 1989). Therefore, ECMO is only recommended for neonates with acute, severe respiratory or cardiac failure with a mortality risk greater than 80%.

With the documented reduction in mortality rates for neonates with PPHN treated with ECMO (Bartlett *et al.* 1982; Bartlett *et al.* 1985; Short *et al.* 1987; O'Rourke *et al.* 1989) there has been a growing interest in examining morbidity and neurodevelopmental outcome in this population. Recently, a number of studies have examined developmental outcome (Towne *et al.* 1985; Glass *et al.* 1989; O'Rourke *et al.* 1989; Adolph *et al.* 1991; Hofkosh *et al.* 1991). Schumacher *et al.* (1991) summarized these studies and found a handicap rate of 10–25% for this population utilizing various indices of mental and motor growth. The authors noted that this range of impairment rate was similar to that for infants suffering severe PPHN who are treated by more conventional medical management (Johnson *et al.* 1974; Bernbaum *et al.* 1984; Ferrara *et al.* 1984; Sell *et al.* 1985; Bifano & Pfannenstiel 1988). Demographic variables and perinatal factors such as gestational age and birthweight appear to have little influence on the incidence of abnormal development among post-ECMO infants (Low *et al.* 1985; Hofkosh *et al.* 1991). Little is known regarding the extent to which treatment variables, such as length of ECMO therapy, are associated with developmental delay. In a relevant study assessing neurodevelopmental outcome for infants with PPHN treated by hyperventilation alone, an inverse correlation was noted between number of days on hyperventilation and level of infant development (Bifano *et al.* 1988).

To date, the literature on developmental outcome following ECMO therapy has not addressed the impact of the high-risk status of these infants on maternal emotional functioning and perceptions of the newborn as vulnerable to developmental delay. There is evidence that serious maternal distress accompanies the birth of a premature, critically ill infant (Kaplan & Mason 1960; Solnit &

Child: care, health and development

VOLUME 21
NUMBER 1

1995

PAGES 53–65

Green 1964; Klaus & Kennell 1970) with more problematic maternal adjustment associated with greater mortality risk (Harper *et al.* 1976; DeVitto & Goldberg 1979; Klaus & Kennell 1970). The range of adjustment problems observed for mothers of high-risk newborns include depression and anticipatory mourning (Benfield *et al.* 1976; Goldberg 1978; Jeffcoate *et al.* 1979), high levels of anxiety (Bidder *et al.* 1974; Perrin *et al.* 1989), feelings of guilt and failure (Prugh 1953; Kaplan & Mason 1960; Solnit & Green 1964) and disruption of normal mother-infant affective bonding (Jeffcoate *et al.* 1979; Plunkett *et al.* 1986). The mood disorders arising from high-risk births can compromise maternal caregiving (Cramer 1976; Harper *et al.* 1976; Waisbren 1980) and may predict persistent maternal distress and difficulties in child rearing (Affleck *et al.* 1982) as well as abnormal child development (Cohen & Beckwith 1979).

The mother's affective reaction to her pre-term infant, and subsequent caregiving practices, may be related to her expectation that the child is at risk of developmental delay (Kennell & Klaus 1982; McCormick *et al.* 1982). Solnit and Green (1964) were the first to describe the 'vulnerable child syndrome' in which a critically ill infant, who survives a life-threatening medical illness without residual handicap, is nonetheless perceived by the parent to be at risk for subsequent illness and abnormal growth throughout childhood. This perception can persist for years despite the child's normal health and professional reassurance that the child's development will be uneventful (Serbin *et al.* 1983; Barnard *et al.* 1984; Perrin *et al.* 1989). Moreover, there is evidence that parent perceptions of infant vulnerability may lower parental expectations for normal child growth (Stern & Hildebrandt 1984), alter caregiving behaviour (Field 1979; Stern & Hildebrandt 1986; Minde *et al.* 1988) and, in turn, affect developmental outcome (Broussard & Hartner 1976; Kearsley 1979).

The literature on maternal distress and 'vulnerable child syndrome' associated with high-risk premature birth is relevant to the study of neurodevelopmental outcome following ECMO therapy. To this end, this study assesses the relationships among selected medical and sociodemographic variables, maternal perceptions of infant development, and maternal distress for mothers of newborns who suffer PPHN and require treatment by either ECMO or mechanical hyperventilation.

Child: care, health and development

VOLUME 21
NUMBER 1

1995

PAGES 53–65

Method

Subjects

Mothers of near-term (gestational age > 34 weeks) neonates born with PPHN and treated in the neonatology intensive care unit at a university medical centre between December 1989 and January 1991 were solicited by phone to participate in the study. Mean age of the infants was 8.74 (3.85) months. Subjects were divided into two groups based on whether their child received ECMO treatment (ECMO) (n = 19) or conventional ventilation (CV) only (n = 15). Since 1986, patients have been selected for ECMO based on the oxygenation index (OI).

$$OI = \frac{\text{Mean airway pressure} \times (FiO_2 \times 100)}{\text{postductal } PaO_2}$$

The normal value is zero; OI > 10 indicates severe respiratory failure; OI > 25 has a mortality of 50% and OI > 40 has a mortality of 80%. Patients are considered for ECMO when OI > 25 and placed on ECMO when the OI is > 40. ECMO neonates received treatment an average of 6.85 (3.45) days in addition to being conventionally ventilated for an average of 13.85 (8.20) days, including an average of 1.90 days of 100% fixed oxygen. CV infants were conventionally ventilated an average of 8.00 (3.63) days, including an average of 1.07 (1.53) days of 100% fixed oxygen. Table 1 presents the means and standard deviations (SDs)

Table 1 Means and standard deviations (SDs) for demographic and perinatal variables for ECMO and CV

Variable	Group	
	ECMO	CV
Age of infant (months)	8.50 (3.47)	9.07 (4.28)
Sex (%male)	60.0%	53.8%
Birthweight	6.61 (1.10)	6.54 (1.92)
Gestational age	38.68 (1.89)	36.80 (2.08)
Mother's age	27.65 (4.21)	28.43 (5.03)
Father's age	31.88 (6.03)	30.89 (4.48)
Mother's education (years)	13.47 (2.65)	13.43 (2.59)
Father's education	14.16 (2.79)	13.64 (3.04)
SES[1]	39.82 (15.36)	43.14 (14.89)
Married	75.0%	64.3%

[1] Note. SES based on Hollingshead Four-Factor Index (Hollingshead & Radlich 1958).
* $P < 0.05$.

for selected demographic and perinatal factors for the ECMO and CV groups. The *t*-tests computed across these factors yielded no group differences for infant age, gender, birthweight, parent's age and level of education, socioeconomic status and marital status. ECMO neonates' gestational period was significantly longer than that of CV neonates ($t = 2.73$, $P < 0.05$).

Procedure

Prospective subjects were contacted by phone to ask if they would be prepared to participate in the study. Written informed consent was obtained and mothers were mailed a number of questionnaires which assessed relevant demographic information, their current psychological status and perceptions of their child's cognitive, psychomotor and social behaviour.

Instruments

Brief Symptom Inventory

The brief symptom inventory (BSI) (Derogatis 1975) is a 53-item self-report inventory which assesses psychological distress across nine dimensions including somatization, obsessive-compulsiveness, interpersonal sensitivity, depression, anxiety, hostility, phobic anxiety, paranoid ideation and psychoticism. A general measure of psychological distress is provided by a global severity index (GSI). Adequate internal consistency and sub-scale validity of the nine scales has been demonstrated (Derogatis & Spencer 1982).

Minnesota Infant Development Index

The Minnesota infant development index (MIDI) (Ireton & Thwing 1980) is a 75-item questionnaire completed by a parent which assesses development of an infant to age 15 months. It yields five scale age-equivalents for measures of gross motor, fine motor, language, comprehension, and psychosocial development. The MIDI has been demonstrated to exhibit good sensitivity to developmental delay, and to yield adequate agreement with the Bayley Scales of Infant Development in a sample of high-risk 8-month-old infants (Creighton & Sauve 1988). For the purposes of this study, developmental quotients were computed by dividing each MIDI scale score by age. Using such quotients, Creighton and Sauve (1988) found that the MIDI gross motor developmental score was the strongest predictor of the Bayley Mental Development Index. Gross motor

developmental quotients of 0.70 or less, therefore, were categorized as indicating delayed development.

Results

Between-group analyses

Developmental outcome

To determine the level of neurodevelopmental functioning, developmental quotients were computed for each MIDI scale and tabulated by group. Percentages of infants categorized as delayed by gross motor quotients of 0.70 or less were 15.0 and 20.0, respectively, for the ECMO and CV groups. These data are comparable to those previously reported in the literature (Schumacher *et al.* 1991). The *t*-tests computed across MIDI scales revealed no differences between groups. Thus, ECMO and CV mothers were similar in their perceptions of their infants' development.

Maternal adjustment

To assess maternal adjustment, standardized *t*-values were determined for each of the BSI subscales and entered by group into a series of *t*-tests computed across the scale scores. No group differences were obtained indicating that ECMO and CV mothers were comparable in their levels of self-reported psychological distress. Examination of the mean *t*-values for both groups indicated that none of the *t*-values for either group exceeded pathological threshold (e.g. $t = 60$) (Derogatis & Spencer 1982).

Correlational analyses

Perinatal factors and developmental outcome

Pearson correlation coefficients computed for both birthweight and gestational age and mother's perception of infant development were non-significant for both groups.

Perinatal factors and maternal adjustment

Similarly, the correlations between perinatal factors and mother's distress were non-significant for both groups.

Length of treatment and developmental outcome

To examine the association between length of intervention and developmental delay, days on ECMO and conventional ventilation for both ECMO and CV groups were correlated with MIDI developmental quotients. Table 2 presents a summary of these analyses. In the ECMO group, the number of days on the ventilator was negatively correlated with all developmental areas, i.e. the greater the number of days on the ventilator the more delayed the development. The number of days on ECMO also significantly predicted developmental delay for all MIDI scales with the exception of language development. As the number of days on the ventilator was strongly correlated with days on ECMO ($r = 0.70$, $P < 0.001$), it was not possible to separate the independent contribution of each treatment modality to developmental delay for the ECMO group. For the CV group, no significant correlations were obtained between days on the ventilator and developmental indices.

Table 2 Correlations between MIDI quotients and days on ECMO and ventilation treatment for ECMO and CV groups

	Groups		
	ECMO		CV
MIDI	ECMO	Ventilation	
Gross motor	−0.58**	−0.66**	0.04
Fine motor	−0.53*	−0.49*	−0.15
Language	−0.39	−0.61**	0.42
Comprehension	−0.59**	−0.61**	0.01
Personal-social	−0.55*	−0.61**	−0.33

* $P < 0.05$.
** $P < 0.01$.

Length of treatment and maternal adjustment in the ECMO group

Significant correlations were obtained when comparing number of days on ECMO and BSI scales. The degree to which ECMO mothers were somatically preoccupied with their own health ($r = 0.48$, $P < 0.05$), reported obsessive-compulsive traits ($r = 0.44$, $P = 0.05$) and complained of general symptom distress ($r = 0.53$, $P < 0.05$) was associated with greater duration of ECMO therapy. Power was insufficient to adjust significance level, but as discussed

below, correlations were in the hypothesized direction, with greater than chance number of significant findings. For the CV group, no significant correlations were obtained when comparing days on the ventilator and maternal psychological functioning.

Maternal adjustment and developmental outcome

MIDI and BSI scales were intercorrelated within group to determine possible associations between maternal adjustment and perception of developmental status. For the ECMO group, no significant correlations were obtained. For the CV group, the perception of language delay included a trend towards correlating with several areas of psychological distress including hostility ($r = -0.54$, $P < 0.05$), and general symptom distress ($r = -0.52$, $P < 0.06$).

Discussion

This study compared neurodevelopmental outcome and concurrent maternal adjustment for neonates suffering PPHN and treated with ECMO or mechanical ventilation. Consistent with the prevailing literature, no differences were observed between ECMO and CV infants on any measure of developmental functioning. The impairment rates of 15 and 20% for the ECMO and CV groups, respectively, are comparable to earlier reports (Schumacher *et al.* 1991) and replicate the limited risk for normal development associated with these interventions. The additional finding that gestational age, birthweight and relevant sociodemographic variables were unrelated to indices of development replicates previous studies (Low *et al.* 1985; Glass *et al.* 1991; Hofkosh *et al.* 1991).

Regarding maternal adjustment, ECMO and CV mothers did not differ in their reports of degree of psychological distress. Both groups on the average were functioning within normal range for the dimensions of affect and personality measured by the BSI suggesting generally positive maternal adaptation following the birth of their high-risk infant.

While the between-group comparisons revealed no main effects for the ECMO and CV groups on measures of infant development and maternal adjustment, correlational analyses indicate associations among indices of development, maternal psychological functioning and ECMO treatment. Perhaps the most important findings pertain to length of treatment for ECMO neonates and associated perceptions of developmental delay and emotional distress for their

mothers. For this group, days on conventional ventilation and days on ECMO both significantly predicted perceptions of delay for virtually all measures of infant growth. No comparable relationship between days on conventional ventilation and perceptions of abnormal development was noted for the CV group, thus differing from the findings of Bifano and Pfannenstiel (1988) who measured time of hyperventilation, an indicator more likely to correlate with compromised cerebral perfusion and oxygenation. The correlation between duration of ECMO and perception of developmental delay may stem from iatrogenic effects of the procedure itself, however, the morbidity rates for the two groups are not consistent with this explanation, nor are previous findings (Hofkosh *et al.* 1991.

Length of treatment also predicted greater maternal psychological morbidity for the ECMO but not CV group. Specifically, ECMO mothers reported more severe global distress, obsessive-compulsive traits and more frequent somatic symptoms. These symptoms can be viewed within the context of sustained, anxiety-toned psychological disturbance and support previous observations of high anxiety levels for mothers of high-risk infants (Kaplan & Mason 1960; Bidder *et al.* 1974; Affleck *et al.* 1982). The fact that maternal adjustment was found to be independent of developmental status for the ECMO group, and that CV mothers were not equally disturbed in relation to the length of treatment for their infants, suggests that the persistent emotional distress reported by ECMO mothers may be due to their view that their infant was 'vulnerable' (Kennel & Klaus 1982). An alternative explanation would be that ECMO, as a highly invasive procedure, is distressing in relation to length of treatment. The lack of significant differences between groups in level of maternal distress argues against this latter explanation.

Defining high-risk infancy in terms of severity of neonatal illness and extent of treatment may help to explain the patterns of maternal distress observed for the ECMO and CV groups. By virtue of the decision to place an infant on ECMO, this population is at high mortality risk and, by implication, vulnerable to maldevelopment in the view of their mothers (Kearsley 1979; Kennell & Klaus 1982; McCormick *et al.* 1982). Therefore, it is understandable that ECMO mothers' distress would be associated with the length of time their child was undergoing treatment for an imminently life-threatening illness. Having survived the trauma of the birth crisis, perhaps reconciling themselves that some residual handicap was to be expected, reactions to subsequent observations of abnormal growth may have been attenuated. Conversely, statistical trends suggest that maternal distress for CV mothers was associated with their perception of abnormal development for their child and not the length of CV

Child: care, health and development

VOLUME 21
NUMBER 1

1995

PAGES 53–65

intervention. Specifically, delayed language development correlated with maternal complaints for global distress and hostility. Comparatively, CV infants were less critically ill at birth and, thus, less likely to be viewed as developmentally at-risk. If so, the perception of developmental delays would be distressing.

This study contains several methodological constraints which limit the validity and generalizability of the results. The sample size was small. The measures of infant development were subjective and vulnerable to influence by a variety of factors unrelated to neonatal behaviour. Specifically, the mother's perceptions may have been influenced by factors independent of the infant's behaviour such as her emotional state or the child's status as a critically ill neonate. However, for ECMO mothers, no association was found between maternal distress and perceptions of infant development. Further, the validity of the MIDI has been described (Creighton & Sauve 1988) and there is evidence that mothers are sensitive to signs of delay in their pre-term newborns as early as 1 month of age and prior to obtaining feedback from professional observers (Minde *et al.* 1988).

As there is evidence that associated maternal factors such as coping with ability (Prugh 1953; Carey 1969) marital satisfaction (Jeffcoate *et al.* 1979; Perrin *et al.* 1989) and the availability of social support (Salter *et al.* 1982) may contribute to a mother's perception of her child as 'vulnerable', future studies should examine these and relevant variables elucidating the complex interactions of mother and infant following high-risk birth.

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Child: care, health and development

VOLUME 21
NUMBER 1

1995

PAGES 53–65