# Parenting Stress and Psychosocial Health in Mothers with Twin–Twin Transfusion Syndrome Managed with Laser Surgery: A Preliminary Study

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'win-twin transfusion syndrome (TTTS) is a severe complication of twin pregnancies with high risk for perinatal mortality and long-term morbidity. This cross-sectional cohort study aimed to determine parenting stress and psychosocial health in mothers with a pregnancy complicated by TTTS that had been managed with laser ablation of communicating placental vessels. Questionnaires were sent to the mothers for completion: Parenting Stress Index (PSI), Edinburgh Postnatal Depression Scale (EPDS) and a semi-structured questionnaire related to mental health problems and support received from health professionals. Thirty-seven mothers were sent questionnaires with 32 being returned. The results showed that 47% of women had total scores equal to or greater than the 85th percentile on the PSI, which is considered abnormally high. Twenty-six per cent of mothers had evidence of depression on the EPDS. Mothers of children with prolonged medical conditions or neurological problems had significantly higher scores (p = .011). Parenting stress was not associated with high scores on the EPDS. Medical and midwifery staff were considered to provide high levels of support, with social work providing none or low levels of support. In conclusion, women whose TTTS pregnancy was managed by laser surgery have high levels of parenting stress. As the results showed that parenting stress cannot be predicted at the time of hospitalization, it is suggested that more support should be provided in hospital with further follow-up after discharge.

Twin-twin transfusion syndrome (TTTS) is the most common major complication of monochorionic twin pregnancy with up to 15% having the polyhydramnios/oligohydramnios sequence. Amnioreduction has been employed for many years in an attempt to prolong the pregnancy and enhance survival. More recently, however, laser ablation of the placental

communicating vessels has been advocated as the preferred treatment for this condition with improved survival rates reported (Gray et al., 2006; Senat et al., 2004). It has been well described that survivors of TTTS are at high risk of long-term, neurodevelopmental disability including cerebral palsy (Cincotta et al., 2000; Lopriore et al., 2003). In terms of neurologic sequelae, however, laser surgery has the potential to improve outcomes, though detailed neurodevelopmental assessment has indicated an incidence of cerebral palsy as high as 5 to 10% (Banek et al., 2003; Graef et al., 2006). Thus while laser therapy for TTTS may confer benefits for infants born following TTTS, the risk of neurodevelopmental disability remains significant.

The birth of a preterm infant results in significant maternal stress and anxiety (Shields-Poë & Pinelli, 1997) which may adversely affect parenting ability (Thompson et al., 1994). Using the Parenting Stress Index, Singer et al. (1999) found that mothers of very preterm infants had more parenting distress compared to mothers of term infants during the first 3 years of life. Twin pregnancy is associated with an increased risk of preterm birth and is likely to result in further high levels of maternal stress in hospital and after discharge (Bryan, 2003), probably related to the extra practical strains in caring for twins in addition to the problems of prematurity. Mothers of twins have been shown to suffer more sleep deprivation and experience more fatigue than mothers of singletons (Taylor & Emery, 1988), with higher rates of depression also reported (Thorpe et al., 1991). Of note, the highest levels of depression were found in mothers whose child had moderate to severe disability and when there was a death in one of the twins.

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Comparisons have been made in parenting stress between parents of twins after assisted conception and those of twins after natural conception with somewhat variable results reported. Cook et al. (1998) found that parents whose children were conceived by in vitro fertilization reported greater stress associated with parenting than parents with naturally conceived twins, while others found similar results only for first-time parents (Baor et al., 2004; Colpin et al., 1999). No assessment of stress and mental health has been reported in mothers with a twin pregnancy complicated by TTTS. It is considered, however, that the TTTS group of mothers will have extremely high levels of stress and adverse psychological measures as there is not only a high risk of prematurity, but also perinatal death and neurodevelopmental impairment.

Accordingly, the present study aims to determine parenting stress and psychosocial health in mothers who had a twin pregnancy complicated by TTTS managed with laser ablation of communicating placental vessels.

### **Methods**

A cross-sectional cohort study of mothers with a TTTS pregnancy managed by laser surgery was performed. The study enrolled mothers from the beginning of the laser program in February 2002 to those who were at least 6 months post delivery in June 2005. They were identified from the TTTS database of the Centre of Maternal Fetal Medicine at the Mater Mothers' Hospital, Brisbane. As the mothers were contacted over the period of a few weeks, the infants were of different ages at the time of the study. TTTS was diagnosed by antenatal ultrasound with the features of polyhydramnios in one twin sac and oligohydramnios in the co-twin of a monochorionic pregnancy. Four women whose pregnancy resulted with both twins dying in utero, or at less than 24 hours of age were excluded. Thirty-nine mothers were thus eligible to take part in the study. Two mothers could not be contacted, with 37 being sent questionnaires. Thirty-two mothers (82%) returned completed questionnaires. The study received approval from the Human Research Ethics Committee of Mater Health Services.

### Procedures

Mothers were sent the following questionnaires for completion.

### Parenting Stress Index (PSI) Short Form (Abidin, 1990)

The PSI — Short Form consists of 36 items and produces a total score of the overall level of parenting stress that a person is experiencing, as well as four subscales. Participants rate each item on a 5-point scale from 'strongly agree' to 'strongly disagree'. The subscales are Defensive Responding, Parental Distress, Parent–Child Dysfunctional Interaction and Difficult Child. Concurrent validity and predictive validity have

been demonstrated for the full-length questionnaire, which is highly correlated with the short form (r = .94).

Mothers were asked to complete a PSI form for each twin. Results were analyzed using the data from the twin with the highest PSI score. Scores at or above the 85th percentile were considered to be abnormally high (Glazebrook et al., 2004)

### Edinburgh Postnatal Depression Scale (EPDS; Cox et al., 1987)

The 10-item EPDS is a well-validated and widely used screening tool for depression after childbirth. It is not diagnostic for depression, but gives an estimate of psychological disturbance. Scores range from 0 to 30, with a cut-off of 12 indicating problems. The EPDS has been used most often for mothers up to 1 year after delivery, but can also be validly employed for greater periods of time postpartum (Thorpe et al., 2003).

## Questionnaire on Mental Health Issues and Treatment and Support Networks

This questionnaire asked for specific information on mental health problems and medication prescribed. Additional questions asked about the level of support received from hospital staff — medical, midwifery and social work, both at the time of laser treatment and after delivery. Practical and emotional support given by family and friends was also ascertained. Participants were given the opportunity to comment further and clarify their responses to questions.

The children have had pediatric follow-up to at least 2 years of age at the Growth and Development Unit, Mater Health Services or by a local pediatrician. Four children have been diagnosed with cerebral palsy, with a further two having medical problems resulting in significant disability (severe hearing impairment; feeding difficulties with a feeding gastrostomy inserted).

As no control group of children could be obtained for this preliminary study, comparisons were made for the PSI — Short Form with the results of an Australian study of oxygen saturation targeting in very preterm infants at the age of 12 months (Askie et al., 2003). Comparisons of the results of the EPDS were made with mothers of twin pairs drawn from the Avon Longitudinal Study of Parents and Children (ALSPAC) who participated in a study of language development (Rutter et al., 2003; Thorpe et al., 2003). Additional analyses were provided from the APSPAC

**Table 1**Parenting Stress Index Scores in the 32 Responding Mothers

		$\geq 85^{\text{th}}$ perc	≥ 85 <sup>th</sup> percentile	
	Mean (SD)	Number	%	
Total Parenting Stress Index	82.3 (19.9)	15	47	
Parental distress	32.0 (8.2)	17	53	
Parent-child dysfunctional				
interaction	21.2 (6.7)	9	28	
Difficult child	29.1 (9.1)	12	38	

**Table 2**Parenting Stress and Maternal Depression in Mothers With Twin–Twin Transfusion Syndrome Pregnancies and Comparison Groups

	TTTS group	Comparison groups	p value
	<i>N</i> = 32	N = 171	
PSI, short form — mean ( <i>SD</i> )	82.3 (19.9)	71.7 (20.6)	.008
	<i>N</i> = 31	<i>N</i> = 96	
EPDS — mean (SD)	9.2 (4.9)	6.1 (5.8)	.005
> 12 (%)	8 (26)	11 (11)	.05

Note: TTTS, twin-twin transfusion syndrome; PSI, Parenting Stress Index; EPDS, Edinburgh Postnatal Depression Scale

data set when the twins were 21 months old (K. Thorpe, personal communication, October 2006).

For statistical analysis, comparison of the results of categorical variables was performed using the chi-squared test and of continuous variables using Student's t test. A *p* value of less than .05 was considered to be significant. Analysis was performed using Statistix 8. No prospective power analysis was performed in this preliminary study.

#### Results

Thirty-two mothers completed the questionnaires when the children ranged in age from 9 to 38 months (mean 20.3 months, *SD* 7.9 months). Six mothers had booked to receive their antenatal care at the Mater Mothers' Hospital. TTTS was diagnosed during routine management. The remaining mothers were referred to the hospital for assessment of severe TTTS from other centers. Laser surgery was performed at a mean of 21.9 (*SD* 2.6) weeks' gestation, with delivery occurring at a mean of 33.5 (*SD* 2.1) weeks. Sixteen mothers delivered at the Mater Mothers' Hospital with the remainder at the referral hospitals. The mean

maternal age at delivery was 30.9 (SD 5.5) years. Of the 32 mothers, 14 were primigravid.

On the PSI, the mean total score was 82.3 (SD 19.9) with 47% of mothers having a score equal to or greater than the 85th percentile (see Table 1). For the subscales, 38% of mothers scored equal to or greater than the 85th percentile for Difficult Child, 28% scored equal to or greater than the 85th percentile for Parent–Child Dysfunctional Interaction and 53% scored equal to or greater than the 85th percentile for Parental Distress (see Table 1). When compared to the comparison group of Askie et al. (2003), the mean PSI score was significantly higher (see Table 2). The mean EPDS score was 9.2 (SD 4.9), with 26% of mothers reporting symptoms suggestive of depression. When compared to the ALSPAC comparison group, the EPDS score was significantly greater (see Table 2).

Seven of the 30 mothers who responded had previous mental health problems. Seven mothers attended a general practitioner for mental health problems since delivery of whom four had no previous reported mental health issues. Six of these mothers were treated with medication.

The association of parenting stress with perinatal and infant characteristics was explored (see Table 3). There was no association with whether or not the pregnancy resulted in perinatal death (p = .63). Furthermore, comparison of parenting stress between donor and recipient twins revealed no significant differences. Parenting stress was not related to delivery before or after 32 weeks' gestation (p = .39) or to the age of the child at the time of questionnaire completion (p = .26). Mothers with no other children had higher levels of stress but this was not statistically significant (p = .55). Mothers of children with prolonged medical conditions or neurological problems had significantly higher Total Parenting Stress Index scores (p = .011). On the Difficult Child subscale there was also a strong relationship to the presence of disability

**Table 3**Parenting Stress Index Results According to Perinatal and Infant Characteristics

	Number of Mothers	Mean Score (SD)	<i>p</i> value
Perinatal death	5	86.2 (23.9)	
No perinatal death	27	81.5 (19.5)	.63
Delivery < 32 weeks' gestation	12	86.1 (22.6)	
Delivery ≥ 32 weeks' gestation	20	80.0 (17.5)	.39
Age of children ≤ 18 months	15	78.6 (20.8)	
> 18 months	17	86.7 (19.1)	.26
No other children	14	84.5 (15.1)	
One or more other children	18	80.5 (23.1)	.55
Child with cerebral palsy	4	97.3 (27.6)	
No child with cerebral palsy	28	80.1 (18.2)	.10
Child with disability	6	100.2 (22.0)	
Child with no disability	26	78.1 (17.3)	.011

Note: TTTS, twin-twin transfusion syndrome

**Table 4**Maternal Support Received from Hospital Staff and From Family and Friends

	High-Medium	Low-None	Total		
Support at time of laser surgery					
Medical	31	0	31		
Midwifery	30	1	31		
Social Work	13	18	31		
Support after delivery					
Medical	25	5	30		
Midwifery	28	2	30		
Social Work	11	19	30		
Emotional support					
Husband/partner	23	2	25		
Family/friends	18	7	25		
Practical support					
Husband/partner	21	4	25		
Family/friends	20	5	25		

(p = .037). There was a trend for parenting stress to be associated with scores greater than 12 on the EPDS (84.8 vs. 81.3), but this was not statistically significant (p = .10). However, on the Parental Distress subscale there was an association with high scores on the EPDS (p = .024).

Medical and midwifery staff were seen for the most part to provide medium to high levels of support at the time of laser surgery and after delivery (see Table 4). 58% of mothers reported none or low levels of social work support at the time of laser surgery and 67% of mothers reported similarly after delivery. Only 25 of the 32 mothers responded to the questions on emotional and practical support. Medium to high levels of both emotional (92%) and practical (84%) support were received from the husband/partner. While family and friends were also reported for the most part to provide emotional and practical support, it was frequently commented that the support diminished over time.

### **Discussion**

The present study examined parenting and psychosocial stress in mothers with a twin pregnancy complicated by TTTS managed with laser ablation of communicating placental vessels. We found that mothers had high levels of parenting stress with almost half having scores on the PSI that have been considered to be abnormally high, with the mean score being significantly greater than that found in an Australian study of preterm infants. Furthermore, a quarter of the mothers had high scores on the EPDS, with the mean score being considerably higher than that found by Thorpe et al., (2003) in the ALSPAC study of twin pairs.

High parenting stress levels have been described in mothers of very preterm infants (Singer et al., 1999).

There is little information, however, on parenting stress in twins (Baor et al., 2004; Colpin et al., 1999; Cook et al., 1998). The studies that have evaluated mothers of twins conceived after assisted compared to spontaneous reproduction have reported somewhat varied results. Colpin et al. (1999) found no differences between the study groups, while Cook et al. (1998) and Boar et al. (2004) reported higher levels of stress in mothers who had conceived by artificial reproductive technologies (ART). It has been suggested that parenting stress in mothers who have conceived by ART may be linked to a history of infertility and perceived loss of self-esteem. Mothers with a twin pregnancy complicated with severe TTTS become aware that the condition is associated with an extremely high rate of perinatal loss and for the survivors, there is a considerable risk of neurodevelopmental disability. While laser surgery offers the hope of improved survival rates and less neurological impairment, the laser surgery could still be considered to be experimental (Fisk & Galea, 2004). Thus it is not surprising that major parenting stress is experienced by many mothers.

In exploring the factors that were associated with parenting stress, it was found that it was only statistically significant for mothers of children with medical or neurological impairment. This would be in accordance with previous studies where mothers of children with disabilities have demonstrated higher levels of parenting stress (Innocenti & Huh, 1992). Singer et al. (1999) found that it was the mothers of very low birthweight infants who had been diagnosed with bronchopulmonary dysplasia in the neonatal period who had the greatest levels of parenting stress. No information was provided, however, on the extent of the disability in this high risk group of infants.

In the present study, whether or not mothers had previous children did not influence the degree of parenting stress. This finding is in contrast to that reported by Colpin et al. (1999) who found that primigravid mothers with twins have increased stress levels compared to those mothers with previous children. It is likely that a pregnancy with severe TTTS results in such high levels of stress, that whether or not it was the mothers' first pregnancy was of little relevance. In contrast to the study of Singer et al. (1999), we did not find the age of the children influenced parenting stress levels. It would seem that the effects on a mother having children following a pregnancy with severe TTTS may be long-lasting.

The assessment of maternal depression was based on the results of the EPDS, with a large proportion of mothers with scores in the range suggestive of psychological disturbance. Furthermore, on comparison with a group of twins born at 33 weeks' gestation or greater, the mothers with TTTS pregnancies had significantly higher scores. Of note, overall parenting stress was not associated with scores suggestive of depression, though perhaps not surprisingly, the Parental Distress subscale was associated with high

scores on the EPDS. A previous study has established a relationship between parenting stress and maternal depression in mothers of children with or at risk of developmental delay (Secco et al., 2006). The direct relationship between parenting stress and maternal depression has not been previously explored for mothers of preterm twins.

The present study is limited in that a control group of mothers with twin pregnancy not affected by TTTS was not available for completion of the PSI questionnaire, though a comparison group of preterm infants (Askie et al., 2003) was available for comparative analysis. The demographic features of the population from which the PSI - Short Form was developed, however, was similar to our group of mothers in terms of maternal age, marital status and race (Abidin, 1990). Additionally no control group completed the EPDS. We used for comparison data on twins from the ALSPAC study in which questionnaires were completed at a similar age to those in the present study. Thus it was considered that the ALSPAC data were appropriate for comparative purposes, even though it was not contemporaneous. Our cross-sectional study was composed of mothers whose children ranged in age from 9 to 32 months. This may have had the potential for bias, though on analysis, parenting stress was not found to be related to the age of the child at the time of questionnaire completion. Another area of potential bias relates to the relatively small sample size which may have led to Type II errors in some of the data analysis.

Overall this preliminary study indicated that women whose TTTS pregnancy was managed by laser surgery have high levels of parenting stress and mental health problems. The results indicated that the parenting stress cannot be predicted at the time of hospitalization, with the best predictor of subsequent difficulties being the diagnosis of a significant neurological or medical problem. It is thus suggested that more support should be provided in hospital to this group of mothers with additional follow-up after discharge. Further research may be required to determine what support is needed to assist parents in coping with this difficult period. Additionally it would be appropriate to undertake longitudinal tracking of parents and children of TTTS pregnancies on a larger population so that more information can be obtained on disability and family psychosocial outcomes

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