How Couples Cope With the Death of a Twin or Higher Order Multiple

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ifty-two Australian couples who had experienced the death of at least one member of a multiple birth (twin or higher order), with at least one survivor of that birth, were interviewed about their experiences at the time of the death, and since. This study compared parents' coping after the twins' deaths using the Beck Depression Inventory II, Perinatal Grief Scale, and unstructured interviews with some structured gueries. Parents provided information on the influence of family, community and medical staff. According to retrospective reports, mothers experienced significantly more depression and grief than fathers at the time of loss. Both parents found the death of their twins grievous, but fathers, unlike mothers, were not encouraged to express their emotions. Although parents generally agreed about what helped them cope, fathers believed that they should be able to cope regardless of their grief. The strength of parents' spiritual beliefs had increased significantly since their loss, and there was some evidence that depressed and grieving mothers turned to spiritual support. Parents whose children died earlier reported levels of depression similar to those reported by parents whose children died later. To date, this is the largest study of grief in couples who have experienced the death of a twin and who have a surviving twin or higher order multiple.

Keywords: twins, bereaved fathers, bereaved mothers, parental grief, child death, multiple birth, depression, spirituality, Beck Depression Inventory, Perinatal Grief Scale

In twin registries, families who have experienced the death of a child, or birth of one with a disability, are far more prevalent (Ong et al., 2006) than in registries of singletons. Using probabilistic record linkage all of the births to each woman (sibships) in Western Australia (WA), during 1980 to 1992 inclusive, were identified (Croft et al., 2002). The WA Twin Child Health (WATCH) study recorded all sibships born during that period in which at least one multiple birth occurred. The establishment of this register and its recruitment methods have been described elsewhere (Croft et al., 2002; Hanson et al., 2000). The Maternal and Child Health Database enabled us to identify all

stillbirths and perinatal, infant and childhood deaths up to the age of 18 years (Stanley et al., 1994). A substudy was conducted to evaluate those families' particular needs (Swanson et al., 2002).

Three studies have reported on how bereaved multiple birth couples cope with their loss compared with coping in couples who had lost a singleton (Netzer & Arad, 1999; Wilson et al., 1982; Wilson et. al., 1985). Wilson et al. (1985) specifically compared mothers and fathers' coping and these authors had, in their earlier paper, pointed out the need for further studies on this subject. It is estimated that although multiple pregnancies comprise 12% of all pregnancies, only 2% survive to term (Hall, 1996). The WATCH study reported 4,748 pregnancies resulting in births of multiples in WA over the period 1980 to 1995 inclusive. These comprised 4,610 sets of twins, 138 sets of Higher Order Multiples (HOM — triplets, quadruplets or quintuplets). In 616 families, one twin or more of the multiples died (Hanson et al., 2003). Through this database, and organizations such as The Compassionate Friends and the Australian Multiple Birth Association (AMBA), we contacted 86 bereaved couples with at least one surviving multiple.

This study is relevant due to increasing numbers of multiple births with their greater mortality and morbidity rates; physical, psychological and sociological complications; and the need for clinicians to understand how to enhance the coping strategies of bereaved multiple birth fathers and mothers.

Increasing numbers of multiple births are reported (Bryan, 1992; Derom et al., cited in Keith et al. 1995; Russell et al., 2003). In 1984 the total number of multiple birth confinements in Australia was 2,395 (2,359 sets of twins and 36 sets of HOM), which represented 1% of the total confinements (231,643) for that year. By 2004 this figure had reached 4,184 (4,105 sets of

Received: 15 April, 2008; accepted: 1 June, 2009.

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twins and 79 sets of HOM), which represented 1.7% of total confinements (250,045) in Australia for the year — a 75% increase over 2 decades (Australian Bureau of Statistics, 2004). In WA, the incidence of triplets increased by a factor of 8.4 between 1960–1964 and 1985–1989 (Petterson et al., 1993; Hanson et al., 2000).

Adding to this trend is the influence of fertility treatments. Records of 6,913 deliveries in the United Kingdom over a 1-week period in 2003 indicated that 96% (including the one set of triplets) were conceived spontaneously, and 1.9% assisted. There were significantly more assisted (13.5%) than spontaneous (1.2%) conceptions in pregnancies resulting in multiples (Bardis et al., 2005). A projection of these multiple birth figures suggests that by 2100, unless curtailed, there could be more multiple than singleton births (Oleszczuk et al., 1999).

Current figures indicate mortality in multiples to be 2.5 times higher than singletons (Kiely et al., 1992; Keith et al., 1995; Russell et al., 2003; Skeie et al., 2003). In the United Kingdom, twins comprise 2% of births, but 9% of perinatal deaths (Bryan, 1996). A systematic review of prognosis for co-twins (excluding higher order multiples) following single-twin death has concluded that for monochorionic (MC) twin survivors, the risk of intrauterine death was six times greater than that of dichorionic (DC) twin survivors. Similarly, the risk of neurological disorders was more than four times higher for MC than for DC twin survivors. Premature birth occurred more commonly (68% versus 57%) in MC compared with DC twin survivors (Ong et al., 2006).

Increased numbers of multiple conceptions require more families to cope with the trauma of infant death. The death of a child destroys a significant piece of the family's hopes and dreams, and a living twin does not eradicate grief for the one who died. Not only are the parents grieving over the loss of their twin child when they bring home only one baby, but also grieving the loss of the status they anticipated as parents of twins (Bryan, 1995; Swanson et al., 2002). Parents are often encouraged to try to forget their dead offspring, and rejoice for the living ones. The distraction of the live children makes ignoring infant death easier for medical staff, family and friends meaning that parents are not well supported by society (Bryan 1992, 1999; Read et al., 1997; Bryan & Hallet, 1997; Simpson & Paviour, 1994; Simpson & Paviour, 2001; Swanson et al., 2002; Wilson et al., 1985).

Grief reactions, often unrecognized by others (Bryan & Denton, 2001), can disrupt parental bonding with surviving children. This 'disenfranchised grief' (Doka, 1989) complicates emotional healing, especially if a decision to undergo fetal reduction was involved (Collopy, 2002).

Depression and Stress

Multiparous women are twice as likely to experience depression after delivering twins when compared with their singleton deliveries (Hay et al., 1990). This may in part be due to the psychological and physical challenges inherent in caring for more than one infant (Fisher & Stocky, 2003; Garel & Blondel, 1992; Garel et al., 1997). Of great importance is that mothers of twins often continue to experience depression 5 years after the death of their children (Thorpe et al., 1991; Simpson & Paviour, 1994). Mothers of twins report five times as much depression and three times as much anxiety than mothers of singletons (Hay et al., 1990).

The father, who generally assumes responsibility for the welfare of the twins' mother, may be illequipped emotionally for the challenge of supporting an exhausted, stressed and depressed woman upon whom both he and his surviving children may depend to keep the family unit functioning well.

Divorce

Recent research indicates that divorce statistics for bereaved parents are similar to the general population (Schwab, 1998). A survey by The Compassionate Friends (1999) found that 72% of bereaved parents in general were married to the parent of their lost child, and in Australia 71% of bereaved mothers of multiples were still with the father of their deceased twins at the time of interview (Swanson et al., 2002). Parents who respond to their infants' deaths according to the societal gender-based expectations (emotive mothers and 'strong' fathers; McKissock & McKissock, 1995) are likely to feel some degree of alienation from each other.

Grief and Consequences of Bereavement for Parents

During 1990–1991, the La Trobe Twin Study (La Trobe University, Melbourne) and AMBA conducted a survey of 200 couples from the initial diagnosis of twins until the infants were 6 months old (Hay et al., 1990). During the survey period, 14 of the 200 couples (7%) lost one or more of their babies, either through miscarriage or perinatally. Parents indicated that they needed varying degrees of information, guidance, help and support. Many, particularly fathers, were not able to grieve openly. Some refused to participate further in the survey after their babies' loss.

Our previous paper on mothers who lost a twin but still had one or more survivors (Swanson et al., 2002) profiled bereaved multiple birth mothers. Among other differences, these mothers suffered significant grief for longer periods than bereaved singleton mothers (Lang & Gottlieb, 1993; Potvin et al., 1989; Zeanah et al., 1995) and expressed more anxiety and depression. Similarly, earlier studies found that mothers and fathers of multiples did not experience significantly less grief compared with parents who had experienced the death of a singleton (Netzer & Arad, 1999; Wilson et al., 1982; Wilson et al., 1985).

Bereaved fathers of multiples are discussed in the literature, but primarily in relation to their affect on the mothers. Their supportive relationship of the mothers has a positive impact on maternal wellbeing and ultimately on quality of attachment to their twins

(Weigel et al., 2000). Fathers who offered unconditional support and affection may actually protect their partners from maternal depression, common after childbirth (Fisher & Stocky, 2003; Smart, 1992; Toedter et al., 1988). Conversely, when partners were controlling yet showed little care for the mothers, there was greater risk of postpartum depression (Matthey et al., 2000). Both parents would like others to initiate discussion with them about the baby (Netzer & Arad, 1999; Wilson et al., 1982). However, mothers and fathers with depressive symptoms have been found to differ in their need for social interaction and in the timing of that need (Wilson et al., 1982; Wilson et al., 1985). In particular, differences occurred during the first 6 weeks after their loss when mothers who had more symptoms of depression were more likely to find their partners helpful and to desire others to initiate discussion of the baby with them. In contrast, the subsequent measure of depression (at a mean of 25 months) found that the fathers' need for social interaction was significantly related to depression scores. The authors speculated that such a delay could reduce the potential for others to recognize the need for help and assist fathers (Wilson et al., 1985). All three studies found that over time the differences between mothers and fathers became less apparent and parental grief diminished (Netzer & Arad, 1999; Wilson et al., 1982; Wilson et al., 1985). However, Wilson et al. (1985) found that mothers continued to report a greater need for social support than fathers.

Method

Participants and Procedure

Between 1999 and 2004, 94 bereaved families with a surviving multiple were identified from the population-based WATCH database. Forty-nine (52%) of these families agreed to participate, whilst a further 17 families were recruited from other sources including bereavement or multiple birth organizations. All of the families were English-speaking Caucasians and represented a wide cross-section of socioeconomic groups, educational backgrounds and career fields.

Data analysis focused on the 52 families in which both the mother and the father had complete data for all of the research variables. Forty-four (84.7%) of the 52 couples were married, 2 (3.8%) were living in de facto relationships, 2 (3.8%) were separated, and 4 (7.7%) were divorced. The mothers' ages ranged from 27 to 58 years (M = 40.69, SD = 6.21), and the fathers' ages ranged from 27 to 61 years (M = 43.58, SD = 7.20).

Letters of invitation along with a description of the purpose and goals of the study were mailed to the bereaved families. Those who responded positively were contacted, and appointments made to meet them in their homes or at a venue they nominated. This allowed time for them to refresh their memories in advance of the time the interviewer arrived to record their stories. After agreeing to participate in the study,

families were sent the Beck Depression Inventory-II (BDI-II; Beck, 1996) to assess depressive symptomatology during the previous 2 weeks (current depression), and the Perinatal Grief Scale: Short Version (PGS-SV; Potvin et al., 1989), to retrospectively rate their emotions at the time of loss. Other demographics collected included: age; marital status; numbers of, and means of, conceptions; and their children's genders and ages. During a subsequent interview, each of the parents was interviewed separately. This interview was designed primarily to collect qualitative data and two additional measures were obtained for the present quantitative study. Parents were given the BDI-II a second time and asked to retrospectively rate their emotions at the time of loss (retrospective depression). They were asked to rate the strength of their spiritual beliefs from 1 (low) to 5 (high) both retrospectively (at the time of loss) and currently.

Measures

Quantitative Measures

The BDI-II (Beck, 1996) is a valid and reliable self-report measure of depression, which contains 21 items each rated on a scale of 0–3. The 21 items yield a total depression score ranging from 0 to 63 with a score of 3–13 indicating *minimal depression*; 14–19 indicating *mild depression*; 20–28 indicating *moderate depression*; and 29–63 indicating *severe depression*. Parents completed the measure twice, taking about 10 minutes to complete it each time: the first with respect to the current time, and the second as they recalled feeling at the time of loss.

The 33-item PGS-SV (Potvin et al., 1989) was originally developed to measure grief and perinatal loss related to death of singleton infants lost after 28 weeks gestation or within 28 days postnatally (i.e., the perinatal period). It is both reliable and valid for this purpose (Potvin et al., 1989), but the authors suggest it could have broader application. In this study, the PGS was administered to all couples, regardless of the age of their children at time of death. Having used this measure for a study with such a broad ranges of 'time to loss,' we then compared the outcome scores for parents whose loss occurred perinatally with scores of those whose loss occurred after longer periods. It contains three 11-item subscales designed to identify 'Active Grief' (normal), 'Difficulty Coping' (more pronounced withdrawal from people and activities) and 'Despair' (serious and long-lasting grief). Subscale scores, which each range between 11 and 55, can be summed to provide a total grief score. Higher scores indicate greater distress. If the deceased were older than a toddler, we changed the word 'baby' to 'twin', making it more suitable for bereaved parents of older multiples.

Qualitative Measures

Unstructured storytelling. Parents were asked at the beginning of the session to 'Please tell your story about the conception, birth and death of your twin'.

Fathers usually had very short stories, and needed gentle prompting to yield a profile of how the loss of their multiple affected them. Mothers, however, generally needed little encouragement to tell a complete and detailed story, often with great insight.

Structured queries. At the completion of the parents' storytelling, the interviewers asked specific questions related to areas that were either untouched or were unclear in the open format. These stimulus questions were derived from the multiple birth literature. They often provided invaluable richness and depth to the individual stories. The open-ended questions included 'What helped you the most? [least?]', 'What recommendations do you have for other bereaved multiple birth parents?'. Questions such as: 'Do you sense a larger purpose for your twin's death?' and 'How do you think loss of a twin is different from loss of a singleton?' also elicited thoughtful responses. Lastly, a structured format asked the parents to respond both currently and retrospectively on a scale of 1 to 5 to a number of aspects. A sample of these are 'ability to deal with whatever happens', 'ability to deal positively with surviving twin [and other children]', 'change in behavior of partner', 'quality of explanation given regarding cause of twin's death', 'quality of medical care received pre and postpartum', 'quality of counseling received when twin died' and 'reliance on external factors (medication, alcohol, counseling, work, and so on) to dull grief and gain comfort with self'.

Focus groups. The purpose of research focus groups is to bring together people to discuss and explore what they know and perceive about a particular experience, topic or product (Glitz et al., 2001). Thus, at the conclusion of most of the formal interviews, interviewees were invited to an evening of sharing and discovery. Firstly, a presentation by the researchers provided an overview of the WATCH study and its findings. Next, trained leaders met with mothers and fathers in small

groups to allow them to respond to our tentative conclusions. This interaction expanded and enriched what we had gathered through individual interviews. Lastly, an informal dinner provided a venue for research participants to meet and interact with other bereaved multiple birth parents.

Data Analysis

The notion that mothers and fathers represent *correlated* samples is consistent with the significant correlations observed between mothers and fathers on three of the six primary research measures (PGS difficulty coping, PGS despair, and PGS total), and on one of the two secondary research measures (retrospective spirituality). Moreover, many of our research questions are about whether the *shared* experience of losing a child impacts similarly on both parents. Such questions are better addressed by treating mothers and fathers as *paired*, rather than *independent*, samples. For this reason, 'parent' is treated as a repeated measures factor in the subsequent data analyses.

Because the aim of the present study was to compare mothers' coping to fathers' coping, data analysis focused on the 52 families in which both the mother and father completed all eight measures, namely: current depression, retrospective depression, PGS total, PGS active grief, PGS difficulty coping, PGS despair, current spirituality, and retrospective spirituality. Quantitative and qualitative data for the complete sample of 66 mothers, including four mothers from New Zealand, have been reported elsewhere (Swanson et al., 2002).

Results

Means of Conception

Thirty-two (61.5%) of the 52 pregnancies were spontaneous and 20 (38.5%) resulted from some form of treatment for infertility. Forty-six (88.5%) of the preg-

Table 1

Mothers (N = 52) and Fathers (N = 52) BDI-III Current and Retrospective Scores: Means and Standard Deviations, and Distributed According to Beck's Classifications

	BDI-II o	current	BDI-II retrospective	
Mothers				
Mean (standard deviation)	8.39	(7.65)	25.12	(13.52)
None or minimal (0–13)	82.7%	(n = 43)	21.2%	(n = 11)
Mild (14–19)	11.5%	(n = 6)	21.2%	(n = 11)
Moderate (20–28)	3.8%	(n = 2)	19.2%	(n = 10)
Potentially serious (29+)	1.9%	(n = 1)	38.5%	(n = 20)
Fathers				
Mean (standard deviation)	7.30	(6.79)	10.53	(7.97)
None or minimal (0–13)	84.6%	(n = 44)	75.0%	(n = 39)
Mild (14–19)	7.7%	(n = 4)	7.7%	(n = 4)
Moderate (20–28)	5.8%	(n = 3)	15.4%	(n = 8)
Potentially serious (29+)	1.9%	<i>n</i> = 1)	1.9%	(n = 1)

Table 2 Correlations Among the Three PGS Subscales and the PGS Total Score for Mothers (Above Diagonal; N = 52) and Fathers (Below Diagonal; N = 52)

	PGS total	PGS active grief	PGS difficulty coping	PGS despair
PGS total	_	.837***	.942***	.871***
Active grief	.894***	_	.728***	.534***
Difficulty coping	.912***	.725***	_	.751***
Despair	.870***	.637***	.720***	_

Note: *** Correlation is significant at the 0.001 level (2-tailed)

nancies produced sets of twins, 5 (9.6%) produced sets of triplets, and 1 (1.9%) produced a set of quadruplets.

Zygosity, Gender, and Morbidity

Parents and adult twins told us their beliefs about zygosity, determined by the number of amniotic sacs, placentae, or multiples' physical resemblance. No families had DNA confirmation of zygosity. Of the 46 twin births, 11 (23.9%) were reported as MZ, 28 (60.9%) as DZ, and 7 (15.2%) were undetermined. Of the 54 multiples who died (two couples lost two triplets, the remaining couples lost one child each), 30 (55.6%) were female and 24 (44.4%) were male. Of the 57 multiples who survived 27 (47.4%) were female and 30 (52.6%) were male. The average time from the death to the time of these interviews was 9.12 years (range 0 to 20, SD = 5.29).

Because 41 (78.8%) of the 52 couples were recruited from the WATCH database, which is linked to other databases (including registrations of deaths) we had accurate information on cause and time of death for their twins. Twenty-six twins (63.4% of the 41 deaths) died in utero or during the first week of life. Of those 26 deaths 17 (65.4%) were stillbirths and 9 (34.6%) occurred during the first week of life. A further four twins (9.8% of the 41 deaths) died within the first month of life; seven (17.1%) died in infancy; and four (9.8%) died between the ages of 1 and 24 years. Due to the small numbers, and the need to preserve the participants' confidentiality, we will not report the causes of death. The other 11 couples were questioned about cause and time of death during the interviews.

Current and Retrospective Depression: Differences Between Mothers and Fathers

A 2 (parent: mother, father) \times 2 (time: current, retrospective) analysis of variance (ANOVA) was conducted on the BDI-II scores. Because mothers and fathers were treated as paired samples, both parent and time were analyzed as repeated measures factors. There was a significant parent by time interaction (F(1,51) = 56.88, p = .000). The nature of this interaction was investigated by analysing the simple main effects of time. Levels of current depressive symptomatology were significantly lower than levels of

retrospective depressive symptomatology for both fathers, F(1,51) = 8.54, p = .005, and mothers, F(1,51) = 120.30, p = .000. The effect, however, was significantly smaller for the fathers: Fathers reported relatively low levels of both current and retrospective depression. In contrast, mothers reported relatively low levels of current depression but relatively high levels of retrospective depression. Table 1 reports the means and standard deviations for these effects.

Table 1 gives the proportions of mothers and fathers reporting 'minimal' to 'potentially serious' current and retrospective levels of depressive symptomatology. Over 84% of fathers reported 'none' to 'minimal' levels of depression in their current ratings, and 75% reported 'none' to 'minimal' levels of depression in their retrospective ratings. In contrast, the mothers' data clearly show much lower levels of current depression than retrospective depression. Less than 6% of mothers reported 'moderate' to 'severe' current depression, but over 57% reported 'moderate' to 'severe' retrospective depression — the difference between the two related proportions is significant, z(N = 52) = 5.19, p = .000.

Perinatal Grief: Differences Between Mothers and Fathers

There were significant positive correlations among the three PGS subscales (viz: active grief, difficulty coping, and despair) and the PGS total score. The correlations are given separately for mothers and fathers in Table 2.

A 2 (parent: mother, father) \times 3 (PGS subscale: active grief, difficulty coping, despair) ANOVA was conducted on the PGS scores. Once again mothers and fathers were treated as paired samples and both 'parent' and 'subscale' were therefore analyzed as repeated measures factors. The parent by subscale interaction was nonsignificant, F(2,102) = 2.47, p =.089, which means that the main effects can be readily interpreted. The main effect for parent was significant, F(1,51) = 49.38, p = .000, indicating that the mean scores for all three PGS subscales were significantly higher for mothers than fathers. The main effect for subscale was also significant, F(2,102) = 250.06, p =.000), indicating that the mean scores for both mothers and fathers decreased significantly from active grief, through difficulty coping, to despair. Table 3 reports the means and standard deviations for these effects.

Relationship Between Depression and Perinatal Grief: Differences Between Mothers and Fathers

The relationship between *retrospective* depression and perinatal grief was examined separately for mothers and fathers using standard regression models with retrospective depression as the dependent variable and the three PGS subscales (viz: active grief, difficulty coping, and despair) as the predictors. Table 3 reports the statistics for the two regression models. There are clear differences between the two regression models: For

Table 3

Mother (N = 52) and Father (N = 52) Regression Models of the Relationship Between Retrospective Depression and the Perinatal Grief Measures, and Between Current Depression and the Perinatal Grief Measures (Means and Standard Deviations for Each of the Grief Measures are Reported in the Second Column)

		Retrospo	Retrospective depression (DV)			Current depression (DV)		
Predictors	Mean (SD)	В	β	sr² (unique)	В	β	sr² (unique)	
Mothers								
Active grief	44.85 (7.01)	-0.017	-0.009	.000	-0.019	-0.018	.000	
Difficulty coping	34.64 (8.69)	0.489	0.314	0.028	0.023	0.026	.000	
Despair	28.35 (8.16)	0.790	0.477	0.099**	0.452	0.482	0.101**	
				$R^2 = .543***$			$R^2 = .242**$	
Fathers								
Active grief	35.79 (8.58)	0.132	0.142	0.009	0.078	0.099	0.004	
Difficulty coping	26.48 (7.77)	0.572	0.558	.113**	0.175	0.200	0.015	
Despair	21.69 (7.31)	-0.025	-0.023	.000	0.023	0.024	.000	
				$R^2 = .425***$			$R^2 = .089$	

Note: ** Significant at the 0.01 level

mothers, despair (not active grief nor difficulty coping) predicted depression. For fathers, difficulty coping (not active grief nor despair) predicted depression.

The relationship between *current* depression and perinatal grief was examined separately for mothers and fathers using standard regression models with current depression as the dependent variable and the three PGS subscales as the predictors. Table 3 reports the statistics for the two regression models. For the mothers, despair (rather than active grief or difficulty coping) once again predicted depression. For fathers, none of the grief predictors were significant.

Time of Death and Time Since Death as Predictors of Depression and Perinatal Grief: Differences Between Mothers and Fathers

Time of death. Parents were partitioned into two groups depending on whether they lost their child before 28 days postnatally (n = 34) or after 28 days postnatally (n = 18). The relationship between *retrospective* depression and time of death (< 28 days, ≥ 28 days) was nonsignificant for both mothers, r(n = 52) = .245, p = .098, and fathers, r(n = 52) = -.099, p = .507. The relationship between perinatal grief (measured by the *total* score on the PGS scale) and time of death was also nonsignificant for both mothers, r(n = 52) = .126, p = .398, and fathers, r(n = 52) = .107, p = .475.

Time since death. The relationship between *current* depression and the number of years that have elapsed since the child died was non-significant for both mothers, r (n = 52) = -.262, p = .082, and fathers, r (n = 52) = .107, p = .475.

Strength of Spiritual Beliefs and its Relationship to Depression and Perinatal Grief: Differences Between Mothers and Fathers

When rated retrospectively, spirituality (i.e., the strength of spiritual beliefs) was significantly higher

for mothers than for fathers: $M_{\rm mothers} = 3.23$, SD = 1.44; $M_{\rm fathers} = 2.40$, SD = 1.28; t(N = 52) = 3.71, p = .001. Ratings of *current* spirituality were also significantly higher for mothers than for fathers: $M_{\rm mothers} = 3.67$, SD = 1.39; $M_{\rm fathers} = 2.74$, SD = 1.46; t(N = 52) = 3.37, p = .001.

The relationship between retrospective spirituality ratings and current spirituality was significant for both fathers, r(N=52)=.723, p=.000, and mothers, r[N=52]=.544, p=.000. The difference between retrospective and current ratings was significant for mothers ($M_{\text{retrospective}}=3.23$, SD=1.44; $M_{\text{current}}=3.66$, SD=1.39; t [N=52]=2.27, p=.028). For fathers, the difference between retrospective and current ratings was not significant ($M_{\text{retrospective}}=2.40$, SD=1.28; $M_{\text{current}}=2.74$, SD=1.46; t[N=52]=1.51, p=.137). Table 4 gives the correlations between strength of spiritual beliefs and depression and perinatal grief for both mothers and fathers.

Qualitative Data – Dominant Themes From Interviews

At the time of loss, and over time, many fathers echoed each other in terms of what was 'most helpful'. Mothers, too, responded much like other mothers in this study. One father reported that 'nothing helped' as his pain of loss was too intense. Another confided the death was positive (a relief) when the handicapped multiple died. Nine mothers reported 'nothing helped' to relieve their intense grief. The common themes are shown below:

Helpful Themes Helpful to Both Parents

- support from partners (mothers or fathers of their deceased twins)
- family and friends who offered acknowledgement and understanding

^{***} Significant at the 0.001 level

Table 4Relationships Between Strength of Spiritual Beliefs and Depression and Perinatal Grief for Mothers (N = 52) and Fathers (N = 52)

	BDI-II current	BDI-II retrospective	PGS active grief	PGS difficulty coping	PGS despair	PGS total
Mothers						
Spirituality now	.319*	.387**	.390**	.362**	.337*	.405**
Spirituality then	0.19	0.182	0.27	0.227	0.162	0.242
Fathers						
Spirituality now	0.133	0.091	.416**	0.226	0.105	.289*
Spirituality then	0.137	-0.018	.389**	0.236	0.224	.322*

Note: * Correlation is significant at the 0.05 level (2-tailed)

- spiritual or religious beliefs
- surviving twins and other children.

Helpful to Fathers

- professional compassion and support (e.g., hospital chaplain, nurses)
- detachment (noninvolvement)
- neutrality (nonresponsive)
- emoting (expressing grief, crying).

Helpful to Mothers

- mementoes of the child, even when stillborn, such as photographs, footprints or a lock of hair
- small acts of kindness from friends and family such as phone calls and assistance with meals and other children.

Hurtful Themes

Hurtful to Both Parents

• insensitive comments: 'At least you've got one', or 'You can have another'.

Hurtful to Fathers

- not seeing the surviving twin [Couple divorced]
- having to be stoic: 'Put on a brave face.'
- immature social worker: 'She asked us for advice about her boyfriend.'
- talking about loss: 'It just makes me sad and emotional'
- looking at mementoes: 'It makes you wonder what he'd be like now.'
- laying blame: 'Looking for a scapegoat'.

Hurtful to Mothers

- seeing live twins: 'Why did I lose one?'
- social workers: 'I was supposed to grieve in a certain way.'
- disenfranchised grief: 'I was not permitted to grieve since I had a live twin.'

- blame: 'My husband blamed me for not having a scan that the doctor did not order.'
- medical staff, especially insensitive doctors: 'Tranquilizers offered, not compassion.'
- paternal non-support (neutrality, detachment or impatience) [Husband said] '... put it to bed [out of your mind].'

Discussion

Summary of Main Findings

The BDI-II showed that fathers experienced relatively low levels of both current and retrospective depression. Mothers also reported relatively low levels of current depression, but reported relatively high levels of retrospective depression. This indicated that, with hindsight, mothers regarded themselves as significantly more depressed at the time of loss, than at the time of interview.

The mean scores for all three PGS subscales were significantly higher for mothers than for fathers. This could relate to mothers' perception of disenfranchised grief at the time of their loss (Doka, 1996). Mothers of twins scored higher also than the mothers of singletons, on which the norms for the PGS are based (Swanson et al., 2002). For both parents, 'active grief' (normal) was higher than 'difficulty coping' (more troubling and longer lasting grief) and 'despair' (severe and long lasting grief) respectively. This was to be expected given that, over time, both parents accommodated their loss into their lives.

Analysis of the intercorrelations among the PGS subscales and total score showed that the correlation matrices for mothers and fathers were equivalent suggesting that the *structure* — albeit not the *intensity* — of perinatal grief is similar for mothers and fathers. That is, mothers and fathers who are low/high on one subscale are also low/high on the other two subscales. It is interesting to note, however, that mothers' correlations are consistently stronger than fathers'.

An analysis of depression and perinatal grief indicated that for mothers 'despair' predicted depression both retrospectively and currently. For fathers, none of

^{**} Correlation is significant at the 0.01 level (2-tailed)

the PGS subscales predicted current depression, but 'difficulty coping' (withdrawing from activities and people) did predict retrospective depression. This could be reflecting fathers' perceptions that society expects them to be able to cope regardless of their own grief and this is reflected in their qualitative comments as to what helped most at the time of their loss — detachment (noninvolvement) and neutrality (nonresponsiveness). Counseling was recommended by the majority of mothers, but generally considered by fathers as unnecessary. Most bereaved multiple birth couples interviewed for this study had received no counseling. Mothers regretted this, but most fathers were firm in disclaiming the need, or in their opposition to it.

Parents whose children died earlier reported levels of depression similar to those reported by parents whose children died later. Retrospective depression and total PGS scores for parents who lost their children perinatally were similar to those who lost children 28 days or more after the birth.

The analysis of parents' spirituality suggested that the strength of parents' spiritual beliefs had significantly increased since their loss — although these effects were very small. Mothers showed significantly stronger spiritual beliefs (both retrospective and current), than fathers. For the mothers, ratings of current spirituality were positively and significantly correlated with depression (both current and retrospective ratings) and perinatal grief. In contrast, ratings of retrospective spirituality were not significantly correlated with any of the depression or grief measures. It appeared that the mothers who currently had the strongest spiritual beliefs were the ones who reported the most grief and the highest levels of current and retrospective depression. The result is inconsistent with the notion that spiritual beliefs reduce levels of grief and depression and is consistent with the notion that depressed and grieving mothers turn to spiritual support.

A different pattern of correlations existed for the fathers, with both current and retrospective spirituality positively and significantly correlated with active (or normal) grief. This implied that fathers professing the strongest spiritual beliefs now and in the past were the ones who were grieving the most. This pattern of results is difficult to interpret: they are inconsistent with the notion that spiritual beliefs reduce levels of grief and with the notion that grieving fathers turn to spiritual support.

By the time of the interview, both parents were generally philosophical about their losses, especially when the multiples were lost during the pregnancy or before their multiples left the birthing center. Fathers did not generally express the view that they were changed by the loss of their twins, unless the loss caused the mother unending grief, disquiet, anxiety or stress. In contrast, many mothers felt their lives were dramatically changed or transformed. They said they

related differently to others and that because of losing a twin they had gained compassion. Their surviving twin was a constant reminder of what they had gained as a multiple birth parent, and of their gratitude for the one who lived. This was especially true with mothers of babies conceived through assisted reproductive technologies, who had invested so greatly financially, emotionally and physically for the privilege of motherhood.

Strengths of This Study

This study included a larger sample size (52 couples) than prior studies where the numbers of multiple birth couples were nine, eight and six respectively (Netzer & Arad, 1999; Wilson et al., 1982; Wilson et. al., 1985). There were no financial or material benefits offered as an inducement to the families to participate in this study. Bereaved multiple birth parents chose to participate as a means of helping those who in future may also experience loss of twins. The majority of the multiple birth bereaved couples represented here were ascertained from an unbiased population database, with a small number having been referrals from reputable twin organizations. The instruments used are well accepted as standard psychological measurement devices and were administered by psychologists (PS and J P-J) trained in their use and interpretation. Families had an opportunity to speak privately or as a group and the interview team were willing to travel anywhere in WA to visit the homes of parents, or to meet them at other locations, allowing families resident in remote and rural WA to be included. The two post-interview focus group sessions were carefully structured to allow families adequate opportunity to: absorb study findings; ask the research team questions; and meet other bereaved parents in an environment where trained personnel could assist in resolving any unexpected emotional issues. These focus groups proved especially valuable in confirming what we had deduced from individual in-depth interviews with parents. Further, the meetings were beneficial to mothers and fathers, as most did not know others who had lost twins, yet had twin survivors.

Weaknesses of this Study

The sample size was restricted by the need to include only families where there was a surviving twin and where both parents had been interviewed. Since the interviews were designed to avoid adding to the distress of the interviewees, if they were unwilling to go on, participants were not pressed to answer every question. Hence not all of the explicit study questions were answered by all of the parents, limiting the number of issues that could be included in the analysis.

This study was conducted some time after the WATCH study was established and hence the elapsed time between interview and the twins' death could vary from just months to more than 20 years, making it difficult to compare some measures of grief across all

families. However, the absence of a statistically significant difference in grief between parents whose loss was in the perinatal period and those whose loss occurred later indicates that these conclusions are still valid.

Finally, families who were willing to participate in a study of coping with death of a twin may constitute a biased sample of the entire population of bereaved twin parents and selection bias may have operated in two ways. First, these participating families may represent the families with the 'best' outcomes, with more distressed families being more likely to refuse to be interviewed. Second, those families who were experiencing little ongoing distress may have refused to participate, as they did not need to talk about their experience any more. The group that we did interview could represent those with the 'worst' outcomes. Without data from the remaining families, it was not possible for us to know in which direction this bias operated.

Strengths and Weaknesses in Relation to Other Studies

To date this is the largest study of grief in couples who have experienced the death of a twin and who have a surviving twin.

Meaning of the Study and Possible Mechanisms and Implications for Clinicians and Policy-Makers

This study provides clinicians and others who work with such families with the first ever, clear guidelines as to what those couples have told us that they wish had happened: at the time of the death; and subsequently. The couples told us that they wished:

- that they had been able to talk to and support each other during their loss
- that clinicians had been more sensitive and compassionate
- that family and friends had been willing to talk about the death and the child who had died.

Unanswered Questions and Future Research

This study and the prior study of grief in mothers of twins (Swanson et al., 2002) were partly designed to assist us in putting together a case for government assistance for these families after a death. We still have not been able to quantify the cost of support services that are needed for these families and a health economist would enhance the skills of the research team. Further research could focus on the health implications of acute and long-term grief for these parents and siblings, using the linked data collections on hospital discharges and other morbidity (such as cancer) that are available in WA.

Conclusions

For many participating parents, their status as fathers or mothers of multiples was unacknowledged until they received an invitation to become part of this study. In summary, we found that bereaved multiple birth families with a surviving twin have special and complex characteristics that affect them in ways greater than, or different from, bereaved single birth families. This study gathered information from bereaved multiple birth couples about how they coped with their losses, together and individually. Mothers' recommendations are reported in the previous paper (Swanson et. al., 2002) but in this sub-study of couples, both fathers and mothers particularly valued:

- support from partners (mothers or fathers of their deceased twins)
- talking, especially with each other.
- family and friends who offered acknowledgement and understanding
- spiritual or religious beliefs
- surviving twins and other children.

Acknowledgments

This study was only possible with the generous contributions of bereaved multiple birth families in WA and New Zealand. Dr Patricia Swanson was supported by a Rotary Ambassadorial International Scholarship for 1 year of the eventual 7-year study period. Captain Carl Swanson provided expertise in men's counseling and conducted interviews with fathers. Curtin University of Technology provided computing, statistical and office facilities and some funds for travel within WA, via the Research Center for Applied Psychology. Appreciation and thanks go to Professor David Hay, Elizabeth and John Spoor, Lyn Dawson, Sue Pilling, Dr Nick Barrett and Dr Kelly Bennett for interview transcriptions, data entry, scoring and analysis.

The WATCH study, which provided data on twins and higher order multiples, was initially funded by a grant from Healthway WA, and then by a grant from the Australian National Health and Medical Research Council.

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