

# How Mothers Cope with the Death of a Twin or Higher Multiple

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Estimates suggest up to 15% of multiples grow up as singleton survivors. Few studies have reported how bereaved multiple birth mothers with a surviving multiple cope with their bereavement. Using the population-based Western Australian Twin Child Health study database and other sources, we interviewed 66 bereaved mothers with at least one surviving multiple. For many, this contact was the first acknowledgment of their status as multiple birth mothers since their loss. The Beck Depression Inventory 2nd Edition (BDI) showed significant reduction in depression between the time of loss and our interview. For mothers as a group there was a high correlation between current and retrospective BDI, and retrospective BDI and all three Perinatal Grief Scales (PGS). There was a significant correlation between the three grief factors on the PGS. When subdivided, this held for mothers who suffered a loss at or before the neonatal period, but not for those whose loss occurred later. Bereaved mothers of multiples scored significantly higher on the PGS than the PGS norm for bereaved mothers of singletons, which we attribute to others not acknowledging their grief, and/or recruitment differences. There were no significant differences in PGS scores related to cause, the time since death, or sibling number or age. Spiritual beliefs and finding meaning in loss were positively related to scores for adjustment and acceptance. Although traumatised, most mothers accommodated their losses meaningfully in their lives. Their own support recommendations are included.

The Western Australia Twin Child Health (WATCH)<sup>1</sup> study (Hansen et al., 2000) compiled a database on all multiples born in the state 1980–1992. Of 7524 multiple births recorded, 3602 sets were twins, 101 triplets, 3 quadruplets and 1 set quintuplets. There were 450 twin deaths — 210 stillbirths and 240 neonatal; 26 triplets died (13 stillborn, and 13 neonatal deaths). There were no quadruplet or quintuplet perinatal deaths. We used this database and other sources to contact bereaved families with at least one multiple birth survivor.

In 1980, twin births represented 1% of all births in Australia. By 2000 this had increased to 1.6% (1 in 72): 3900 multiple births (Australian Bureau of Statistics, 2001). Therefore, by extrapolation, one child in 36 is a twin (i.e., one Australian in 12 is affected as a parent, sibling or co-twin). Increasing numbers of multiples are conceived using Assisted Reproductive Technology (ART) (USA Centers For Disease Control, 1999; Parazzini, 1994), which poses particular risks for morbidity (Hansen et al., 2002), and mortality (Daniel et al., 2000).

Modern medicine provides the expectation that babies will survive the womb and thrive after birth. However it is well known that twins and higher multiples, however conceived, are at greater risk than singletons for complications before, during and after birth. It has also been estimated that although multiple pregnancies comprise 12% of all pregnancies, only 2% survive as twins to term (Hall, 1996a) as many are lost early in pregnancy as miscarriages or as the vanishing twin syndrome. It has been suggested that post-conceptual nondisjunction might lead to chromosome imbalance, disorganisation of embryonic growth, fatal fetal malformation, and vascular compromise (Hall, 1996b).

Physical or intellectual disability in some twin survivors represents a second loss — the loss of a healthy child, creating additional stress to families. Furthermore ART (intracytoplasmic sperm injection and in vitro fertilization) children in Western Australia (WA) were shown to have over twice the incidence of major birth defects (Hansen et al., 2002; Mitchell, 2002) as those conceived naturally.

The incidence of cerebral palsy (CP) in WA is 0.2% in singletons, 1.3% in twin pregnancies (6.5 times singletons'), and 7.6% in triplets (38 times singletons') (Petterson et al., 1993). When one or more babies die in utero in twin or triplet pregnancies, the rate of CP in survivors rose to 10% (50 times singletons') and 29% (145 times singletons') respectively. Monochorionic placentas also pose extra risk for multiples. Beal (1983) found that Sudden Infant Death Syndrome (SIDS) is greater in twins than in singletons.

When one of twins or higher order multiples (HOMs) dies perinatally, parents are often encouraged to forget their lost child and celebrate the living child or children. Although anxious to talk about their loss, parents are frequently discouraged from doing so due to the discomfort of others. (Bryan, 1999; Read, Bryan & Hallett, 1997; Simpson & Paviour, 2001). Not only are parents grieving over the loss of their child, but also perhaps the loss of their status as parents of twins. Many feel their "specialness" has been diminished or eliminated by bringing home fewer babies than expected. For these reasons, the grief of bereaved multiple birth mothers may be underestimated and perhaps be different to that of bereaved mothers of singletons (Bryan, 1995; 1996).

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Health professionals tend to avoid bereaved multiple birth parents, adding to their distress. This avoidance may be due to inadequate training concerning multiple pregnancies as well as discomfort with death. Even when bereaved parents of multiples were satisfied with prenatal and birthing care, they were more dissatisfied than bereaved singleton parents with the support they received after loss of a child (de Kleine et al., 1995).

Using the Perinatal Grief Scale (PGS) to compare the grief of parents of twins to those of singletons Cuisinier et al. (1996) found that parents whose twins were in neonatal intensive care units were as intensely affected by the loss of their babies as were parents who lost singletons, and that mothers showed more grief than did fathers.

The relatively higher morbidity and mortality of multiples, together with the associated complications of attachment (Ostfeld et al., 2000; Pickle cited in Levy, 2000), depression (Thorpe et al., 1991), and mourning (Segal, 1999), make bereaved multiple birth families an important aspect of our understanding of human reproduction and its impact on families and society in general.

This study explores the nature of the bereavement in mothers who lost one or more of their twins, triplets or quadruplets, their means of coping and ways in which bereaved multiple birth families may be better supported.

### Participants, Materials and Methods

Ninety-four bereaved families with a surviving multiple were identified from the population-based WATCH database (1980–1992), 49 (52%) of whom participated. Seventeen mothers (26%) were recruited from other sources including bereavement or multiple birth organisations. Four New Zealand (NZ) mothers contributed written stories. All the families were English-speaking Caucasians. They represented a wide cross-section of socioeconomic groups, educational background and career fields. Most (74%) of the participants were residents in WA's capital city, Perth.

Sixty-six mothers were interviewed between 1999 and 2001; three-quarters were from the WATCH database. The study included interviews with other members of the family but only data from the mothers are reported here.

#### Quantitative Devices

The Beck Depression Inventory — II (BDI-II) (Beck, 1996) is a reliable and valid measure of depression that is self-administered and takes approximately 10 minutes to complete. Its 21 items yield a total depression score, with each item rated on a scale of 0–3. “Minimal” depression is a score of 3–13; “Mild”, 14–19; “Moderate” 20–28; and “Severe”, 29–63. All mothers were invited to complete it. Eighty three per cent (retrospective) and 87% (current) responded. The Perinatal Grief Scale: Short Version (PGS) (Potvin et al., 1989) contains 33 items developed to measure perinatal loss, bereavement and grief. Its 33 items are categorised in three subscales of 11 statements each. These factors are Active Grief (normal grief), Difficulty Coping (withdrawing from activities and people, indicating more severe depression), and Despair (potentially serious and long-lasting grief).

Subscale items are interspersed throughout the device. It has an alpha coefficient of .97, corrected item total mean correlation of .52, highly satisfactory construct validity, and internal reliability.

The PGS was standardised on mothers who had had a singleton perinatal death, defined in their study as a fetal death after 28 weeks gestation or a neonatal death within 28 days of birth. However, they stated that the scale could be useful in assessing the depth and severity of grief in those who have become bereaved earlier or later, as well as for other kinds of loss. In our study, we encouraged mothers to complete the scales if the death had occurred at any time during the pregnancy and through the early toddler period — 85% of our mothers did so. Some mothers of older twins declined, expressing discomfort with the 11 items containing the word “baby”.

When a family agreed to an interview date, they were sent the BDI-II to gauge depression during the previous two weeks (current) and the PGS to retrospectively rate their emotions at the time of loss. Parents were encouraged to complete these in advance to stimulate memories they might share in the subsequent interviews. In the interview they were asked to score the BDI-II a second time, according to how they rated their feelings at the time of their loss.

#### Qualitative Device: Interviews

The qualitative interview format consisted of three components. In the first respondents were asked, “Please tell me your story”. This was often all that mothers required to produce a detailed account of the multiples’ conception, pregnancy and the ultimate outcome. This was followed by a series of stimulus questions. These were developed from the twin loss literature or evolved from themes raised by the first ten mothers interviewed. Questions included, for example, “What recommendations do you have for newly bereaved parents who have lost a twin or higher multiple?”; “What helped you most/least, then and now?”; and “Do you sense a larger purpose for your twin’s death?”. The third section called for responses, retrospective and current on a 5-point scale (1 being *low*), to a series of items ranging from “spiritual beliefs”, extent of “acceptance of circumstances of the twin’s death” to “the quality of counselling received when their twin died”, “ability to deal positively with the father of their twins”. The more structured approach often elicited aspects mothers had not mentioned in open-ended story telling.

#### Focus Groups

After collection of interview data, families were invited to join focus groups. This was to share the study results, check our findings, and to provide an opportunity for them to meet other bereaved families.

### Results

The 71 families interviewed represented multiples in 77 pregnancies (70 sets twins; 6 sets triplets, and 1 set quadruplets). One family had two sets of twins, one of each surviving. Three families lost both of their first set of twins, but both of a second set lived; one family lost two of a set of triplets and one of a set of twins.

**The Mothers**

Ages ranged from 24 to 71 years ( $M = 42.71$ ,  $SD 8.88$ ). Of the 66 WA mothers interviewed, their status in relation to the father of their multiples was: 71% married, 1% separated, 8% never married, 3% in de facto relationships, and 17% divorced. The four NZ mothers were married.

**Means of Conception**

Of 64 pregnancies with data, 60% were spontaneous, and 40% resulted from some form of treatment for infertility.

**Zygoty, Gender and Morbidity**

Parents and adult twins told us their beliefs about zygoty, determined by the number of amniotic sacs, placentas, or multiples' physical resemblance. No families had DNA confirmation of zygoty. Thirty per cent were reported as MZ, 56% DZ, and 14% unknown.

Of the 81 multiples who died, 34 were male, 40 female, and 7 of unknown gender. Of the 82 who survived, 42 were male and 40 female.

**Ages, and Causes of Death**

Because 74% of our mothers were recruited from the WATCH database, which is linked to other databases in WA, we had accurate information on time and causes of these deaths (10% miscarriage; 31% stillbirth; 29% neonatal; 27% postneonatal; 3% childhood). Some of the 26% of mothers not on the WATCH database were uncertain of time or cause of deaths. Figure 1 shows causes of all deaths reported by mothers. Table 1 shows age for all post neonatal deaths.

**Time Since Death**

The average time between death and interview for the 66 mothers was 11.8 years ( $SD=6.5$ ; range 2.5 months–41 years). Table 2 gives a breakdown of time since death.

**Surviving Co-multiples**

At the time mothers were interviewed, co-twins (42 male, 40 female) were aged 2.5 months to 65 years (0–5 years, 12.6%; 6–11 years, 32.3%; 12–16 years, 30.8%; 17–27 years, 14%; 28–39 years, 2.8%; 40–55 years, 2.8%, 56+ years, 4.7%).

**Singleton Siblings**

At the time of death of the multiples (excluding surviving co-multiples), 51% of families had no older children, 20% one, 18% two, 8% three, and 3% four.

**Table 1**

Ages and Gender of Twins Who Died: SIDS; Drowned; Illness; Suicide

SIDS ( $n = 9$ )	Drowned ( $n = 2$ )	Illness ( $n = 5$ )	Suicide ( $n = 2$ )
Months	Months	Years	Years
2 (female)	8 (male)	4 (female)	23 (MZ female)
3 (female)	30 (male)	5 (male)	40 (MZ female)
4 (male)		7 (male)	
4 (female)		18 (female)	
5 (male)		19 (male)	
5 (female)			
5 (male)			
10 (male)			
14 (female)			

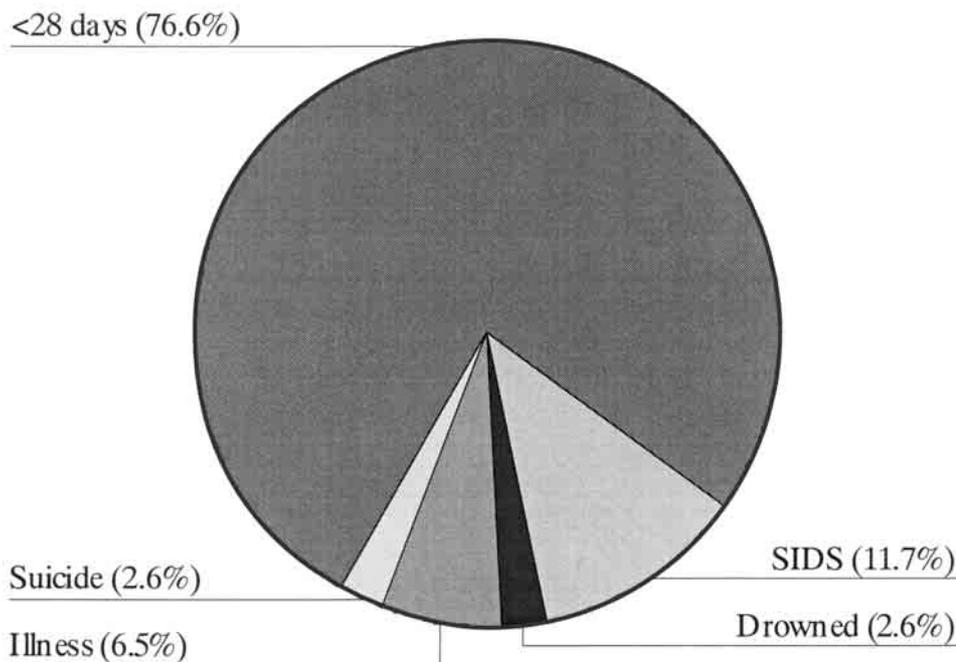


Figure 1 Causes of death as reported by mothers.

**Table 2**

Time Between Loss of Multiples and Mothers' Interviews

Years	Percent and number <i>N</i> = 66
0–1	5% ( <i>n</i> = 3)
2–5	12% ( <i>n</i> = 8)
6–10	33% ( <i>n</i> = 22)
11–15	29% ( <i>n</i> = 19)
16–20	18% ( <i>n</i> = 12)
21–41	3% ( <i>n</i> = 2)

**Mothers' Current and Retrospective Depression and Grief**

One-way analyses of variances (ANOVA's) and *t* tests for independent and paired samples were used to compare mean scores of mothers on the grief and depression inventories. They are divided into groups for some analyses, which is described later. Spearman's rho was used for correlations. All results were evaluated at the Bonferroni adjusted alpha-level. Because some items evolved in the course of interviews, and some deaths occurred after the perinatal period, the number of mothers varied on some factors.

For mothers as a group, current depression scores were significantly lower than retrospective  $t(n = 60) = 9.99, p = .0001$ . Table 3 gives the distributions of BDI scores according to the author's classifications.

There was a significant correlation between depression current and retrospective; between retrospective depression and factors PGS Total, Active Grief, Difficulty Coping and Despair; and also between BDI current and Despair. All grief scales were significantly correlated. Active Grief mean was higher than Difficulty Coping, and Difficulty Coping higher than Despair. Correlations are shown in Table 4.

To compare depression and grief in mothers whose loss occurred before 28 days postnatally, and those whose loss occurred at a later age, mothers were then divided into two groups: those who experienced loss "Early" (Intrauterine, Perinatal, Neonatal, Congenital, Stillbirth), and those who lost their multiples "Later" (SIDS, Drowning, Illness, Suicide). For the group of mothers who suffered an Early loss there was a significant correlation between the BDI retrospective and PGS Total  $r(n = 41) = .74, p = .001$  and grief factors Active Grief  $r(n = 41) = .61, p = .0001$ , Difficulty Coping  $r(n = 41) = .71, p = .0001$ , and Despair  $r(n = 41) = .65, p = .0001$ . There was a significant correlation between the factors Active Grief and Difficulty Coping

**Table 3**

Mothers' Rating of Depression: Retrospective and Current

	BDI-II Retrospective	BDI-II Current
Minimal	24.7% ( <i>n</i> = 15)	81.5% ( <i>n</i> = 53)
Mild	18% ( <i>n</i> = 11)	9.3% ( <i>n</i> = 6)
Moderate	18.2% ( <i>n</i> = 11)	6.1% ( <i>n</i> = 4)
Severe	39.3% ( <i>n</i> = 24)	3.1% ( <i>n</i> = 2)
Total	100% ( <i>n</i> = 61)	100% ( <i>n</i> = 65)

$r(n = 43) = .78, p = .0001$ , Difficulty Coping and Despair  $r(n = 43) = .78, p = .00001$ , and Active Grief and Despair  $r(n = 43) = .61, p = .0001$ .

For mothers whose children died Later, there was a significant correlation between retrospective and current depression  $r(n = 15) = .66, p = .007$ . There was also a significant correlation between retrospective depression and PGS Total  $r(n = 15) = .89, p = .001$  and Despair  $r(15) = .84, p = .001$ . There were no significant correlations between grief subscales.

Using one-way ANOVA there were no significant differences in depression or grief between these Early and Late groups of mothers, although all scores of the Later group were higher than those of the Early group

We compared scores of our bereaved multiple birth mothers with scores of the 138 bereaved singleton mothers recruited from obstetrical and gynaecological settings upon whom the PGS was standardised (Potvin et al., 1989). Mothers of multiples scored significantly higher on all scales than did the norm group. Statistical significance remained between mothers of twins and singletons when mothers of multiples were divided into Early and Later deaths. As Cuisinier et al. (1996) do not report the scores of their multiple birth or singleton mothers, we could not compare our results with theirs. For our mothers of multiples and Potvin et al.'s singletons Active Grief was the highest score. (See Table 5).

**Strength of Spiritual Beliefs**

There was a significant correlation between spirituality and the extent to which mothers believed their loss served a greater purpose  $r(n = 50) = .39, p = .006$ . All five mothers who regarded themselves as low (1/5 or 2/5) on current spirituality saw no greater purpose.

We compared spirituality and finding purpose in loss in mothers who suffered an Early versus Later loss. (Refer back to Figure 1 for proportions).

Of those whose loss occurred before 28 days postnatally, 66% rated themselves as high on spirituality; 10% low; and 24% did not have strong feelings in either direction. 44% felt strongly that their loss served a greater purpose; 46% strongly that it did not; 10% were neutral.

For those whose loss occurred when the multiples were older, 77% rated themselves high in spirituality, 8% as low, and 15% were indifferent. Seventy-three per cent felt there was a greater purpose; 27% felt there was no greater purpose. There were no significant differences in depression and grief between mothers who felt there was a greater purpose and those who did not.

**Interviews — Important Themes**

A number of mothers said that when newly diagnosed with twins or Higher Order Multiples (HOMs) they worried about how they would care and provide for more than one baby.

Mothers reported high anxiety and grief when multiples died in utero in the second, and especially the third, trimester. Unlike single foetal deaths, labour was not induced for fear of loss of the remaining babies. Mothers said that when they went into labour, medical staff appeared uneasy with attending deliveries with known complications.

**Table 4**  
Correlations Between Bereavement and Grief Measures

	BDI-II Retrospective	BDI-II Current	PGS Total	Active Grief	PGS Difficulty Coping	Despair
Retrospective	—	.444** <i>p</i> = .0001 <i>n</i> = 59	.703** <i>p</i> = .0001 <i>n</i> = 54	.527** <i>p</i> = .0001 <i>n</i> = 54	.625** <i>p</i> = .0001 <i>n</i> = 54	.685** <i>p</i> = .0001 <i>n</i> = 54
Current		—	.400** <i>p</i> = .002 <i>n</i> = 57	.203 <i>p</i> = .130 <i>n</i> = 57	.332 <i>p</i> = .012 <i>n</i> = 57	.455** <i>p</i> = .001 <i>n</i> = 57
PGS Total			—	.810** <i>p</i> = .0001 <i>n</i> = 57	.919** <i>p</i> = .0001 <i>n</i> = 57	.869** <i>p</i> = .0001 <i>n</i> = 57
Active Grief				—	.710** <i>p</i> = .0001 <i>n</i> = 57	.584** <i>p</i> = .0001 <i>n</i> = 57
Difficulty Coping					—	.690** <i>p</i> = .0001 <i>n</i> = 57
Despair						—

Note: \*\* Significant

**Table 5**  
PGS Scores of Mothers on This Study, and Scores of Mothers Who Were Recruited After the Loss of a Singleton (63 Spontaneous Abortion, 18 Ectopic Pregnancy, 39 Fetal Death, 18 Neonatal Death, Potvin et al., 1989)

		PGS Total	PGS Active Grief	PGS Difficulty Coping	PGS Despair
Mothers of Multiples	<i>M</i>	106.44 ( <i>n</i> = 56)	44.07 ( <i>n</i> = 56)	34.11 ( <i>n</i> = 56)	28.26 ( <i>n</i> = 56)
	<i>SD</i>	23.66	8.46	9.26	9.10
Mothers of Singleton	<i>M</i>	82.10 ( <i>N</i> = 138)	35.75 ( <i>N</i> = 138)	24.09 ( <i>N</i> = 138)	22.26 ( <i>N</i> = 138)
	<i>SD</i>	23.61	10.14	9.03	7.41
		<i>t</i> ( <i>n</i> = 194) = 6.51, <i>p</i> = .0001	<i>t</i> ( <i>n</i> = 194) = 5.42, <i>p</i> = .0001	<i>t</i> ( <i>n</i> = 194) = 6.95, <i>p</i> = .0001	<i>t</i> ( <i>n</i> = 194) = 4.14, <i>p</i> = .0001
Multiples Early	<i>M</i>	103 ( <i>n</i> = 43)	43.16 ( <i>n</i> = 43)	32.6 ( <i>n</i> = 43)	27.1 ( <i>n</i> = 43)
	<i>SD</i>	7.61	8.44	9.09	8.36
cf. Singletons		<i>t</i> ( <i>n</i> = 181) = 6.54, <i>p</i> = .0001	<i>t</i> ( <i>n</i> = 181) = 5.46, <i>p</i> = .0001	<i>t</i> ( <i>n</i> = 181) = 6.99, <i>p</i> = .0001	<i>t</i> ( <i>n</i> = 181) = 4.80, <i>p</i> = .0001
Multiples Later	<i>M</i>	116.46 ( <i>n</i> = 13)	46.46 ( <i>n</i> = 13)	37.85 ( <i>n</i> = 13)	32.15 ( <i>n</i> = 13)
	<i>SD</i>	22.39	8.38	8.34	10.10
cf. Singletons		<i>t</i> ( <i>n</i> = 151) = 5.04, <i>p</i> = .0001	<i>t</i> ( <i>n</i> = 151) = 3.70, <i>p</i> = .0003	<i>t</i> ( <i>n</i> = 151) = 5.28, <i>p</i> = .0001	<i>t</i> ( <i>n</i> = 151) = 4.45, <i>p</i> = .0001

Mothers were also concerned about prematurity, which interrupted early bonding with hospitalised twins, sometimes lasting months. In self-defence against greater emotional pain, some mothers said they resisted bonding with babies whose chances of survival were gravely threatened. Increased vigilance caused tension, and decreased joy in caring for fragile survivors once at home. Many low birth weight (LBW) and very low birth weight (VLBW) infants survived, but some had developmental delays and other handicaps. Mothers of the 13 surviving twins with morbidity appeared the most stressed at interview, though, not more depressed nor grief-stricken as measured quantitatively.

Mothers were very aware of the quality, high or low, of the attention they received from medical practitioners who diagnosed the pregnancy and death or treated, delivered and provided aftercare for their newborns. There was a

marked contrast between mothers who attended King Edward Memorial Hospital for Women (KEMH), WA's only tertiary level maternity hospital, and those attending other units.

KEMH is now equipped to respond immediately, medically and spiritually, to birthing crises. Its long-term chaplain has a reputation amongst these mothers for compassion and care. They said he guided them in how to cope with their grief, and assured them they were blameless for their losses. KEMH ensured that bereaved parents received mementoes of their lost multiples. Parents were also encouraged to bathe, dress and hold their dead babies and helped, if desired, to arrange their babies' farewells from their homes.

By contrast, mothers who lost their twins a decade or more ago expressed — through tears — that they had few or no mementoes; were prevented from seeing and handling

their babies; and had little, if any, involvement in making the final arrangements. This, they felt, denied them access to and resolution of their grief.

#### After Loss: What Helped; What Did Not

All responses of mothers were pooled to find what they said was “most helpful” and “least helpful” to them at the time of their losses. The most common themes of “most helpful” were 1) Surviving children; 2) Acknowledgement and understanding from family and friends; 3) Support from father of twins; and 4) Spiritual or religious belief. Nine mothers felt that their grief was so intense that “Nothing helped”.

They said least helpful were:

1. Unacknowledged (disenfranchised) grief, (e.g., “But you still have one.”; “It’s God’s will.”).
2. Insensitive comments, (e.g., “You are young; you can have another”; “You need to get on with life.”).
3. Social workers’ interactions (e.g., “She kept pursuing ... telling me I had to go through a grief process in a certain way”; “She tried to be too personal — closed in on me.”).
4. Seeing live twin pairs (e.g., “My heart hurts when I see twin babies.”)
5. Lack of support from the twins’ father (e.g., “You’ve got your daughter; my son died.”).
6. Medical staff (e.g., “I tried to get autopsy report, but always failed — doctor ‘cold’.”; “The doctor offered me tranquilisers, but not willing to talk about it.”).
7. Being blamed (e.g., “Blame is useless, but we all blame ourselves.”; “He [husband] blamed me for not having a second ultrasound, but the doctor did not suggest it.”).

All mothers indicated awareness that their lives had been transformed by their losses. Most said they were positively changed. They felt themselves to be more caring, thoughtful and compassionate, less materialistic and less likely to “take anything for granted”.

#### Mothers’ Recommendations

Recommendations to others who have lost a multiple were consistent. The most frequent recommendations were:

1. Become involved with others as soon as possible.
2. Join multiple birth bereavement groups such as the Australian Multiple Birth Association Bereavement Support Group (M-BABS)<sup>2</sup>. (Bereavement groups not specific to multiples were considered less helpful).
3. Ban blame.
4. Plan and participate in a final ceremony for lost twins.
5. Grieve actively.
6. Write about your losses.
7. Love others, especially partners and family.
8. Name the deceased twins.
9. Search for spirituality, or faith in a higher power.
10. Look for meaning in your loss.
11. Seek medical and psychological help.

12. Talk to sympathetic, compassionate listeners.

Other (often deceptively simple) kindnesses they saw as “gifts” from caring others were: ongoing phone and letter contact; attendance at memorial services; and volunteer help with home and children.

Not all mothers who made these recommendations had *actually practised* these active coping strategies. Many had neither sought nor had counselling. They regretted that they handled their grief “the hard way” — alone. The minority who had received skilled, professional counselling, spoke of the benefits.

#### Focus Groups

Three groups of WA mothers ( $n = 18$ ; 27% of sample) (plus an aunt and two grandmothers) have attended focus groups. More are planned. All the mothers expressed appreciation for validation of the uniqueness of their situations and in particular for being asked, often for the first time, to tell their stories as *they* had lived them. We could find no significant differences between mothers who chose to and those who did not attend focus groups on any factors analysed.

#### Discussion

This cohort of bereaved multiple birth families is unusual, if not unique, in that most (74%) of the families were identified from a population database.

Because parents of multiples still have a child when one dies, many people including some doctors, assume they grieve less than bereaved singleton parents. The unanticipated intensity of grief multiple birth mothers described made clear that this was not true, although there was a reassuring drop in depression over time.

Our results demonstrate that concern about the physical and emotional health of bereaved multiple birth mothers is justified (Scholz et al., 1999). The increasing numbers of multiples births, particularly HOMs, resulting from ART are of particular concern. The majority of ART mothers in our study were not fully aware of the sobering statistics, such as the risk of complications in multiple pregnancies, the likelihood of preterm delivery, low birthweight infants with their increased risk of neurological and other disorders. Many felt betrayed by the medical establishment and were unprepared for the deaths and disabilities of their babies, and for the grief that usually followed. Our data indicate that, like bereaved mothers of singletons, mothers of multiples show higher levels of Active Grief (i.e., normal) than Difficulty Coping (withdrawal), and more Difficulty Coping than Despair (chronic grief). For bereaved multiple birth mothers as a group, the high correlation between the three grief factors of the PGS is consistent with findings of Potvin et al. (1989) on their bereaved singleton mothers, suggesting that this measure is valid for use with bereaved mothers of multiples. This held for Early loss, where depression and grief at the time of loss were highly correlated, as were correlations between all three grief factors. For Later loss, there were no significant correlations between grief factors: The only significant correlation was between retrospective depression and Despair, and PGS Total and Despair. This may reflect actual differ-

ences in grief responses between these two groups of multiple birth mothers, or that, for bereaved mothers of multiples, the PGS is not valid for use for loss after the neonatal period. We found significantly higher PGS scores in our sample compared to that of the singleton mothers of Potvin et al. (1989). Cuisinier et al. (1996) found that the grief of mothers who lost a newborn twin was equivalent to that of mothers who lost a newborn singleton. Because their mean scores are not reported, we cannot compare our findings with theirs. If our mothers' scores differed significantly from those of Cuisinier et al. this may relate to differences in recruitment methods. Both Potvin et al. and Cuisinier et al. recruited from clinical or hospital settings, whereas most of our mothers were recruited from a population based twin register. In addition, Cuisinier et al.'s sample was bereaved within 6 months to three-and-a-half years of interview, and Potvin et al.'s approached for participation 6 to 8 weeks after their loss. Our range, by contrast, was 2 months to 41 years (average 11 years), which may in part explain differences in findings.

A limitation of our study was that the assessment of depression and grief was retrospective, which may account for our high grief scores relative to Potvin et al. (1989) and Cuisinier et al. (1996). Alternatively, our findings may reflect cumulative disenfranchised (unacknowledged) grief, and/or changing attitudes towards bereaved parents. Future research should explore this further.

Mothers were very conscious of the extent of compassion and understanding given them by medical staff and others who counselled them. They were also very sensitive to whether or not they felt blamed for their losses. Their appreciation of this supports a study of parents of SIDS children: Self-blame, or blaming others, indicates continuing distress and thus interferes with healing. (Downey et al., 1990).

Our findings concur with those of two findings of a Swedish study that assessed mothers two to three years after singleton stillbirths. Those who saw their dead children as much as they wished, and kept tokens connected to them, experienced significantly reduced anxiety and other "adverse" psychological affects compared to controls (Radestad et al., 1996). Read et al. (1997) and others have described how photographs, footprints and clothing are precious reminders to bereaved parents.

In our study some mothers mentioned being treated with lack of understanding by young, inexperienced social workers. They believed it would be wise for maternity hospitals to employ mature staff who were conscious of the heightened sensitivity this responsibility requires for effective support of bereaved multiple birth mothers. Many of the active and externally directed recommendations advocated by our bereaved mothers, such as loving others, have been described by Videka-Sherman (1982) as "adaptive coping". Those in our study who practised adaptive coping strategies expressed the greatest positive adjustment to their losses.

Many mothers were distressed when people did not recognise that surviving co-twins were twins, or referred to their surviving triplets as "twins", or quadruplets as "triplets". When asked how many children they had, many were ambivalent about responding because they sensed they

would cause discomfort. They also felt jealousy and envy (and occasionally bitterness) when they saw others with two or more multiples.

Mothers of same sex twins generally were not curious about zygosity at the time of loss. Many regretted they were not advised by medical specialists to obtain this information that might be medically, psychologically, and historically useful to their families, especially to the living multiples.

#### **Spiritual Beliefs: Search for Meaning in Loss**

There were no differences in depression and grief between mothers who believed there was a greater purpose for their losses and those who did not. This supports findings of Davis et al. (2000) that search for meaning may be helpful, but not a prerequisite for adjustment after loss. Our quantitative and qualitative data suggested that mothers who assumed spiritual beliefs and meaning for their losses expressed less bitterness, blame and regret than those who did not. Mothers who lost multiples Later, who expressed high spirituality and found meaning in loss (in contrast to Early loss mothers), may reflect a greater need to have faith in a higher or cosmic order to help them accept the tragedies that took lives of twins they had loved, nourished and known longer after birth.

#### **Disenfranchised Grief**

"Disenfranchised grief" — grief unacknowledged by others (Doka, 1989) — was experienced by a large majority (67%) of our mothers. They were also so absorbed in the care of the surviving multiples that they had little time to contemplate their losses. Furthermore, since others encouraged them to feel fortunate that they still had one or more living children, they lacked permission to grieve. Several were more accepting only after the birth of a subsequent child. Studies of singleton deaths indicate that the birth of another baby could be helpful in easing maternal grief (Dyregrov, 1987).

Lack of acknowledgement (disenfranchised grief) might explain the significantly higher grief scores of mothers of multiples compared to those of mothers of singletons in Potvin et al. (1989). Their experience may have been more intense than bereaved mothers of singletons in part because of the constant reminder of loss in their twin survivors. In focus groups, most mothers said that this was the first time since their twins died that they were being recognised as mothers of multiples. Many wept for the first time about their loss, during or soon after our interviews.

#### **Response to Death**

Not surprisingly we found that those bereaved mothers who had experienced years of infertility and the associated challenges (emotional, physical and financial) of ART appeared to suffer more intense distress than those who conceived naturally.

Mothers reported a wide spectrum of reactions to their loss, from relief to chronic depression. The few mothers who expressed relief were those who had "only wanted one (or one more) baby", and those who felt they could not cope with two or more infants simultaneously. Generally mothers who were deeply depressed were those who, if not

initially overjoyed at the diagnosis of multiples, became so during pregnancy.

In this study, mothers accepted with relative ease (but deep wistfulness or regret) a first trimester loss of a twin resulting in no or minimal visual reminder at birth of the vanished or deceased twin. It was more difficult if the death occurred in or after the second trimester. Mothers who were expected to contribute to a decision to turn off life support were particularly taxed, especially if this contradicted their religious beliefs.

### Life After Loss

All our multiple birth mothers who experienced perinatal deaths spoke of the painful contradiction of grief and joy. Those who best adjusted to loss were those with a network of friends and/or family support. The multiples' fathers were of paramount importance, grandparents a close second. Older siblings were a strong comfort, as were the surviving multiples.

Characteristic of mothers who adjusted to life after twin loss were those who appeared to experience "transformative grief" (Doka & Schneider, 1996), which connects "hardy" people to their spiritual core, enabling them to connect more positively to others and to be more flexible in dealing with their own lives.

Many mothers believed their initial grief was more intense and painful than that of fathers. Though mothers indicated higher levels of positive (and lower negative) emotions in the present compared to the time of their twins' deaths, they still felt their grief more enduring than that of fathers.

This agrees with Gray's (1993) conclusion that men and women have significantly different emotional responses to life. When fathers were unable to recognize and meet the emotional needs of mothers (at least minimally) their relationships were arguably compromised by the deaths of multiples. Nonetheless, 72% of our mothers at time of interview had been in partnership with the fathers of their multiples for 3 to 25 years (average, 14 years).

Their relationship stability is contrary to findings that suggest a higher than average divorce rate among bereaved parents in general (Klass cited in Clarkson, 1992). It may be that those who were in supportive relationships were more inclined to participate in our study.

Mothers were excessively strained when their lives and expectations changed after the death of their twins. They needed to: a) express their emotions about their losses openly; b) have their grief accepted despite having surviving multiples; c) be respected as mothers whose grief is normal, not pathological; d) be reassured of the ongoing love and devotion of their partners and families e) to be given time to grieve; f) be supported unconditionally in how they expressed their grief, such as visiting the twins' graves.

Whether the lost children are multiples or singletons (Cuisinier et al., 1996; Potvin et al., 1989), the loss is powerful, intense and lifelong for mothers. But for most mothers the grief seems to lessen in its intensity over time, in both groups, and they do manage to accommodate the loss. The latter is contingent upon time, and (signifi-

cantly) permission for a normal grief reaction when the loss occurs. This finding agrees with William Worden's (1982, 1991) and Klass's (1999) descriptions of normal grief reactions and complicated mourning.

Mothers strongly confirmed the hidden nature of their bereavement, and clearly experienced catharsis as a result of involvement with this study. This therapeutic effect appears to be ongoing as interviews began three years ago. Mothers finally felt their grief was acknowledged as legitimate.

### Conclusion

The death of a twin appears to be as great a loss for a mother as the death of a single baby, and perhaps often more traumatic. The risks of multiple pregnancies with ART merit wider publicity. Bereaved mothers of multiples need special support, especially when first confronted by the reality of their changed lives after the deaths of twins. The transition of mothers through their grief would be assisted by heightened sensitivity in their carers, as well as the wider community. Like many who have suffered highly significant losses, most of the mothers felt that through their grief they had been permanently changed, even transformed. In loving and losing their multiples they had grown more sensitive and compassionate.

"In so many ways, loss shows us what is precious, while love teaches us who we are" (Kubler-Ross & Kessler, 2000; p. 222).

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### Footnotes

- 1 The West Australian Twin Child Health (WATCH) study, commenced in 1997, was undertaken to establish a population-based twin register that initially included all multiple births in the state 1980-1992. Linked to Maternal and Child Health Records and other health-related databases (Death Register, Hospital Morbidity Database, Birth Defects and Cerebral Palsy Registers) it is maintained by the TVW Telethon Institute for Child Health Research.
- 2 M-BABS was formed in Australia in 1997, but most mothers in our study were not aware of its existence at the time of interview. It publishes a newsletter, "Multiple Dreams", for bereaved families. M-BABS (2002) also recently published its first newsletter, "Embers" as "A Publication Sustaining the Supporters of Bereaved Multiple Birth Families".

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