

# Multiple Birth Families With Children With Special Needs: A Qualitative Investigation of Mothers' Experiences

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Multiple birth remains prevalent, with prematurity and subsequent disability being common complications. However, little is known of the experiences of mothers living with the combined circumstances of multiple birth, prematurity, and special needs. This paper reports an exploratory study using the qualitative technique of thematic analysis, to describe and interpret the experiences of 10 mothers of prematurely born multiple birth children with diverse special needs. Mothers were shocked to learn they were carrying multiple fetuses, including those who underwent in vitro fertilization with dual embryo transfer. Most experienced protracted concern over one or more babies' survival during pregnancy, and prescribed bed rest was frequently associated with increased anxiety and other adverse psychological effects. Some experienced disenfranchised grief, such as those grieving the opportunity to bear a single child. The contrast with experiences of mothers of healthy, term singletons caused considerable distress. Feelings of detachment and unreality were common in the immediate postpartum period, possibly due to transient depersonalization. Having more than one newborn created practical and psychological problems during the neonatal period, particularly when infants were separated due to differences in medical status. The extent to which hospitals accommodated the multiple birth relationship varied and significantly affected mothers' postnatal experiences. Mothers often felt guilty, particularly regarding inequality of care and attention they were able to provide to each child. This was especially problematic for multiples discordant for special needs status. The presence of one normally developing child complicated adjustment to the other's difficulties, and several experienced chronic sorrow. Serious maternal mental health difficulties were common but not universal. Available formal supports were generally perceived as inadequate, addressing some, but not all, of the mothers' needs. Further work is needed to advance understanding of the relationships between mothers and their multiples, and to explore the implications of special needs within multiple birth families.

■ **Keywords:** multiple birth, twins, mothering, special needs, disability, prematurity, thematic analysis, qualitative

## Background

A sharp increase in multiple births was noted worldwide in the latter decades of the last century, primarily due to increased uptake of assisted reproductive techniques (ART) (Umstad & Gronow, 2003). The rate of multiple births peaked in Australia in 2002 at 16.5 twins per 1,000 births. This has recently fallen to 15.5 per 1,000 births. The rate of spontaneously conceived twins rose slightly in 2008, from 11.8 per 1,000 births in 1995 to 12.8 per 1,000 births (Lancaster et al. 1991; Laws et al. 2008; Umstad & Lancaster

2005). Simultaneously, the rate of ART-resultant twins rose substantially from 177.1 twins per 1,000 births to a peak of 210.4 per 1,000 births in Australia in 2001. This has

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recently fallen to 96.4 twins per 1,000 births, primarily as a consequence of policies of single embryo transfer (Laws et al. 2010).

As recently as 2005, ART accounted for 22.5% of all multiple births, from just 4% of all conceptions. This rate has recently fallen to 17.1% of all multiple births from a similar number of conceptions (Wang et al., 2010). Similar reductions in multiple birth rates have only occurred in the United Kingdom since 2008 and are yet to be seen in the United States (Minutes of Human Fertilisation and Embryology Authority Meeting, 2010; Centers for Disease Control and Prevention, 2010). Delayed childbearing continues to contribute to the high number of multiple pregnancies, but has less impact than assisted reproduction (Tough et al., 2002; Wang et al. 2010).

Multiple birth families are intensive consumers of health-care services, from preconception onwards. Premature birth and subsequent need for neonatal intensive and/or special care are frequent complications of multiple pregnancy, with 56.7% of twins and all triplets born before 37 weeks, and 11.2% of twins and 27.3% of triplets before 32 weeks (Laws et al., 2010). Neonatal mortality rates for multiples in the Australian state of Victoria were 6.4 times those of singletons in 2007 (Consultative Council on Obstetric and Paediatric Mortality and Morbidity, 2010). While their use of medical resources before, during, and after birth is high, multiples have contributed greatly to medical knowledge through participation in twin studies.

Surprisingly, prevalence of disability among multiples is poorly documented to date, but is expected to be substantial, largely due to increased prevalence of prematurity. Twins have a 5- to 10-fold increased risk of cerebral palsy (Pharoah, 2006), and are at increased risk of congenital malformations (Glinianaia et al., 2008). Language difficulties and behavioral problems are more frequent in multiples (Hay et al., 1987; McDougall et al., 2006). The reasons for such difficulties are not yet well understood, but may reflect a combination of factors such as diminished opportunity for parents to engage in one-on-one interaction with their children, multiple birth children imitating a comultiple's faulty language or challenging behavior, and neurodevelopmental consequences of shared gestation.

Maternal physical morbidities of multiple gestation are well documented, and include three- to fourfold risk of pre-eclampsia and eclampsia, doubled risk of ante- and postpartum hemorrhage, and sixfold risk of preterm birth (Umstad & Gronow, 2003). Maternal psychological morbidities are less widely recognized, but nonetheless prevalent (Fisher & Stocky, 2003). In one study of mothers of multiples at 3 months postpartum, 43% described themselves as being anxious, 30% depressed, and 76% exhausted (Hay et al., 1990). Increased risk of depression persists beyond the postnatal period, with mothers of twins three times more likely to be depressed at 5 years (Thorpe et al., 1991). Mothers of multiples are significantly overrepresented in admissions to

Australia's unique residential mother-baby units, for reasons such as maternal exhaustion, depression, and anxiety (Fisher et al., 2005).

Mothers of (singleton) children with disabilities are at risk of carer fatigue (Leonard et al., 1993) due to increased physical and emotional workloads. The term 'chronic sorrow' has been used to describe the lifelong feelings of sadness experienced by some parents of children with disabilities, as they reflect on the discrepancy between their child with a disability, and the child without a disability who might have been (Olshansky, 1962; Teel, 1991). The experience of parental bereavement has been explored within the psychosocial literature about multiple birth, (Cuisinier et al, 1996; Swanson et al, 2002). In families with a multiple birth child with special needs (where 'death' is symbolic), there is a major disenfranchised loss, an experience which in some respects parallels bereavement.

There is a very modest literature regarding the health and well being of mothers of a multiple birth child with a disability. De Vos and colleagues published an exploratory study of 15 twin-pair families, (twins aged between 9 and 18 years), in which one twin of each pair had an intellectual disability (De Vos et al., 2002). Although a standardized measure of parenting stress was administered, results published were limited to the mothers' acceptance or non-acceptance of their child's disability, and whether or not they conceptualized their children as twins. Mothers in this study indicated that they faced additional problems during their twins' early years. Yokoyama (2003) noted that of mothers using ART, those with at least one multiple birth child with a disability were more than twice as likely to have depressive symptoms than those with no multiples with a disability.

Despite the prevalence of multiple birth and the increased risk of disability among multiples, very little is known about the experiences of mothers living with both circumstances (that is, multiples *with* a disability). Literature regarding multiples with special needs (as it exists in books and pamphlets published by multiple birth associations) is essentially derived from expert opinion, rather than research. Due to paucity of research into this population, clinicians have little evidence upon which to base care which is sensitive to their presumed specific needs.

Although at odds with 'person-first' terminology, the use of the word 'multiples' to describe children of multiple birth is well accepted within the community to which this study relates and is not considered offensive in this context (e.g., 'Expecting Multiples?' heading on the home page of the Australian Multiple Birth Association's website (<http://www.amba.org.au>)).

## Objectives

This exploratory study was designed to investigate the experiences of mothers of young multiple birth children with

diverse special needs, and to identify common challenges, shared perspectives, and experiences of healthcare.

## Method

### Setting

The study took place through the Royal Women's Hospital in Melbourne, Australia's largest specialist hospital, which provides care to women and newborn babies. Services include a specialized Multiple Pregnancy Clinic and Neonatal Intensive Care Unit.

### Study Design

A qualitative study design was chosen, as an effective means of initiating exploration of an inadequately described phenomenon (Pope & Mays, 1995). This study was conceived as the initial phase of a two-part mixed methods inquiry into parenting of multiple birth children with special health-care needs, a design with considerable precedent in health research (Morgan, 1998).

### Recruitment and Participants

Participants were mothers of young multiple birth children (hereafter referred to respectively as 'mothers' and 'multiples'). All multiples had received care in a tertiary-level Neonatal Intensive Care Unit (NICU) and/or Special Care Nursery. Multiples were aged between 12 months and 6 years (corrected for prematurity) at the time of recruitment. Eligibility was confirmed using the 'Children with special health care needs screener' (Bethell et al., 2002), a brief instrument with robust psychometric properties (Carle et al., 2011). Mothers who otherwise qualified but who were unable to converse comfortably in English were excluded, as were bereaved mothers of multiples with only one survivor. Mothers for whom the principal researcher (a trainee pediatrician) had previously provided clinical care were excluded, as were those known socially by the principal researcher (herself the mother of identical twins). Two consultant neonatologists (otherwise unconnected with the study) were briefed on the study's aims and criteria for participation and suggested potential participants. These women were sent an Invitation to Participate letter from the referring neonatologist. Those who did not return a response form within 3 weeks were contacted by a research nurse. Women indicating interest in participation were sent detailed Participant Information and Consent Forms. The women were asked to contact the researchers by telephone, at which point eligibility was confirmed and an interview appointment arranged.

### Data Sources

Data were collected by individual interviews with 10 mothers of multiples with special needs. Participants were limited to 10, for manageability of data. Pseudonyms have been used in reporting results. All interviews were conducted by CEB. Questioning was non-directive and open-ended, and was

informed by psychological theories relating to grief, attachment, and child development. Significant maternal distress was framed as a normal response to significantly distressing circumstances.

A schedule of topics was prepared for use in the event of a mother's conversation stalling; this proved unnecessary. An introductory 'ice-breaking' question was used for each interview ('Can you tell me about how you first found out you were having twins/triplets?').

### Procedure

Mothers were offered a choice of interview modalities and locations: face-to-face (in the mother's home, at the hospital, or at another location suggested by the mother), or telephone interview.

The study was approved by the Human Research and Ethics Committees of the Royal Women's Hospital, Melbourne, and the University of Melbourne. Mothers could pause or stop the interview at any time. A protocol was developed for suggestion of counseling options for mothers in case of identified need.

### Data Management and Analysis

Interviews were digitally recorded and transcribed in full by the interviewer. Each interview was checked for accuracy by listening to the recording while reading the transcript. Mothers were offered the opportunity to edit their transcripts. Approved transcripts were transferred to a qualitative software management program (NVivo 8, QSR International Pty Ltd. [2008]) to facilitate analysis. Transcripts were summarized to allow rapid identification of key elements, however the majority of analysis used full transcripts. Repeated reading of transcripts was undertaken. Choice of themes and sub-themes was data-driven (derived directly from what the mothers said), as the alternative approach (using theory-driven themes) relies on the existence of a relevant body of research, lacking in this instance. Analysis was inductive (moving from observation to hypothesis) rather than hypothesis testing or deductive.

The qualitative technique of thematic analysis was chosen, as a 'useful approach in the exploratory or discovery stage of a study' (Boyatzis, 1998), and particularly useful when investigating an underresearched area (Braun & Clarke, 2006). The analytic process followed the phases of thematic analysis as outlined by Braun and Clarke. The software program was employed to assist sorting interview excerpts into categories ('generating initial codes'). Many excerpts (which ranged in length from a few words to several paragraphs) were coded under multiple categories. Categories were then themselves placed into conceptually related groups ('searching for themes'). The process of reviewing groups and defining overarching themes was iterative and reflexive.

Given the interviewing researcher's own experience as a mother of premature twins (a fact of which potential

participants were apprised in their 'Invitation to Participate' letter), it was necessary to remain mindful of the potential for interpretation bias. This was minimized by discussing evolving findings with coresearchers, and using a modified form of 'member checks' (Kirk & Miller, 1986), discussing findings with two other mothers of multiples with special needs, who were not study participants.

## Results and Discussion

### Response to Recruitment

See Figure 1. One mother was excluded, being known socially by the interviewer. Another appeared unaware of her child's diagnosis of cerebral palsy when non-response was followed up by the hospital's research nurse. She was felt not to be an appropriate participant, and feedback was given to her child's pediatrician. The self-referred participant, who had learnt of the study from another participant, and who also met selection criteria, was recruited following verification with the relevant ethics committees.

### Participants

#### Data Collection

See Table 1. Interviews were conducted over a 3-month period in mid-2009. Three mothers were interviewed in their own homes, three at the hospital, and four underwent telephone interview. Written consent was obtained at the time of interview (if face-to-face) or by mail (telephone interviews). Interviews ranged in duration from 45 to 90 minutes. Five mothers requested and received a copy of their transcripts, but none requested changes. None requested or required referral for counseling as a result of participation.

#### Reliability and Validity

Some data triangulation was possible, with mothers' experiences and interpretations being echoed on online multiple birth parenting forums and in peer support literature. Analysis remained 'close to the data', using participants' own words to illustrate concepts wherever possible. The interviewing researcher's twin mother status was considered significant by most participants (with comments such as 'Well, you know how it is' being typical); rather than being detrimental, it is likely this enhanced rapport, improved disclosure, and enhanced reliability. Findings of the current study were both similar to those reported in the multiple birth and special needs literature, and make a novel contribution.

Each mother's story followed a clear chronology. This allowed grouping of data under 'phases' corresponding to key stages in mothers' experiences of multiple motherhood. Superimposed on these phases were a number of overarching themes, which became more or less prominent at different times in each mother's story. For example, for some mothers, the impact of special needs was profound during pregnancy (if she learned antenatally of potential problems), for

others, this featured heavily after discharge from hospital, as problems became apparent.

Although in practice these themes overlapped, a brief overview of each will be given separately. Each major heading incorporated several sub-themes, and was subjected to detailed separate thematic analysis. The following is a summary only.

**Diagnosis of multiple pregnancy.** Mothers were invariably shocked to learn they were carrying multiples, even when they had undergone in vitro fertilization and had two embryos transferred. They were equally likely to be happy, ambivalent about, or appalled by the news.

'Really excited, really special and exciting, but at the same time, HOW are we going to do this?' (Jess)

'Bloody hell, you know, two! I really didn't want two. No one would have two out of choice.' (Nina)

Interestingly, two mothers who volunteered negative reactions (including Nina, above) had elected dual fresh embryo transfer. Both had previously borne a singleton following dual *frozen* embryo transfer, and had expected a similar outcome this time. Findings of this study echo previous reports (Bryan, 2005; Spillman, 1985) that diagnosis of multiple pregnancy, including those conceived using ART, may be a source of considerable distress for parents. Their initial distress was often compounded by responses from strangers, family, and friends that they were 'doubly blessed', and would be fortunate to have an 'instant family'. The assumption that bearing two children simultaneously was either desirable or sufficient was erroneous for many. For those who had struggled to conceive, the term 'instant' was insulting.

For three mothers (two first-time, one second-time), the diagnosis of multiple pregnancy, in fact represented a profound loss—the loss of their imagined 'one-to-one' mother–baby relationship. Mothers could not express their sorrow at this loss — because to outsiders they were 'lucky' to be pregnant with multiples (particularly when they had previously suffered infertility). This is a form of disenfranchised grief — 'a grief that persons experience when they incur a loss that is not or cannot be openly acknowledged, socially sanctioned, or publicly mourned' (Doka, 1989). This sentiment was echoed on a multiple birth online forum, in a discussion entitled 'Grieving for the singleton I never had, and never will have':

'I had and still have those feelings. I wasn't 'allowed' to have them though. I had to put on a show of forever being blessed and grateful for two babies.' (Anonymous, 2006)

**The multiple pregnancy.** In popular western culture, pregnancy is often portrayed as a period of contentment; pregnant women are said to be 'glowing'. In contrast, this

was seldom a happy time for mothers in this study. Their pregnancies were characterized by three patterns:

1. 'Great' or 'okay' ( $n = 4$ )
2. Severe morning sickness, followed by a 'honeymoon' period ( $n = 4$ )
3. Severe morning sickness, then early, serious complications ( $n = 2$ )

Eight mothers had known their pregnancy was 'high risk'. Most mothers experienced prolonged uncertainty over one or more babies' survival, and six experienced bed rest, ranging from 5 days to 15 weeks.

'I'd been so sick with morning sickness, I thought nothing could've survived in there.' (Anne)

'I'd cry every night, but I knew I didn't want to let go.' (Hana)

Three of the mothers on prescribed bed rest volunteered crying 'a lot', especially at night. Another became so anxious she lost her voice for a month, which may have been an example of the dissociative phenomenon described as psychogenic aphonia (Kollbrunner et al., 2010). Another was unable to walk for several days after birth due to physical debilitation. Another continued to suffer post-traumatic stress symptoms on the anniversary of commencing bed rest 4 years previously. The potential for bed rest to affect expectant women's mental and physical well being adversely is well documented in the nursing literature (Gupton et al., 1997; Maloni et al., 1993), including those with multiple pregnancies (Maloni et al., 2006). However, this research did not seem to have yet translated into enhanced supportive practices for these mothers.

Two mothers described anguish at having been accommodated on shared wards with women who had recently given birth, before their own babies' premature births.

'They put me in a room with three other mums who'd had caesars, and so the whole night, I was just crying, listening to these mums with their babies.' (Anne)

The contrast between the 'norm' and the mothers' own experience was profound. Several expressed feelings of guilt that they were 'letting their babies down' by their inability to carry them to term.

One mother was extremely upset by advice from an unfamiliar obstetrician immediately prior to emergency caesarean at 28 weeks that she should 'just let him [growth restricted twin] die'. Multiple gestations did not render any of the babies more 'expendable' than if the pregnancy were singleton; this was not always appreciated by family or care providers. This echoes the finding of Cuisinier and colleagues (1996), that grief in bereaved parents of twins should be taken as seriously as grief in bereaved singleton parents.

**Birth of multiples.** All multiples were premature, with gestations ranging from 24 weeks 3 days to 33 weeks 6 days. Only two mothers were offered choice of mode of delivery, the others appeared not to have been distressed by their lack of choice. Most births (6/10) were by emergency caesarean section, and no mother regretted having had caesarean births. Other research has found caesarean birth to be associated with increased risk of adverse psychological outcomes (Fisher et al., 1997; Rowe-Murray & Fisher, 2001); it may have been that the high-risk nature of these mothers' pregnancies rendered them more comfortable accepting any intervention offering their babies the best chance of a healthy outcome. This notion is frequently echoed in online discussions of women pregnant with multiples:

'As long as they come out nice and healthy, what does it matter?' (Anonymous, 2009)

Mothers were struck, but not particularly troubled, by the sheer number of attendants at the birth, and frequently described their babies being 'whisked away'.

'It was a bit of a circus.' (Katrina)

'I just remember there were a million people there, but I didn't really care.' (Nina)

They often felt very alone once the excitement and activity of the birth was over, and their babies were gone. Several found the contrast between their own postnatal experience and that of happy, term, singleton mothers particularly distressing:

'The first night was really quite revolting, being in this room with five other women who all had their babies with them, and sitting there going 'Where are MY babies?' And hating that feeling.' (Katrina)

**Postnatal period (neonatal intensive care and special care).** Feelings of emotional detachment and unreality were common in the immediate postpartum period. This may have been transient depersonalization, and has been described previously in the context of traumatic singleton, term delivery (Boudou et al., 2007). Women experiencing depersonalization in this setting have been shown to be at increased risk of developing post-traumatic stress disorder (Olde et al., 2005).

'That weekend is a complete blur to me. I don't remember much of it, because I think I was in complete shock.' (Jill)

'I was overwhelmed. . . It was like it was all a blur.' (Hana)

'It all gets a bit of a blur from now on. . . I don't remember really.' (Katrina)

Mothers were often horrified by their babies' initial appearance, intimidated by medical equipment and confused by medical jargon.

'You look TERRIBLE! And ugly! And where's my big, fat, beautiful babies?' (Anne)

'I saw him with the tube. . . He looked like a dead rat. He just was still, with his arms in the air, and that's what I can see.' (Cath)

'When I first saw them, I just thought, 'Oh, what have I done?'" (Jill)

Not being able to touch or hold their babies was 'excruciating'. A mother's need to have physical contact with her infant in the nursery has been consistently reported in the literature (see review in Cleveland, 2008). An additional 'layer' of need existed for several mothers in this study, who also wished for their babies to have the opportunity to touch each other. There is a modest evidence base to support co-bedding of premature twins. One randomized controlled trial demonstrated improved weight gain within the co-bedded group (Chin et al., 2006) and another study, fewer central apneas in a co-bedded group (Touch et al., 2002).

All mothers were discharged from hospital before their multiples, with the gap between mothers' and babies' release ranging from 7 weeks to 8 1/2 months.

I think the hardest thing was coming out of hospital, after having them, and having no babies. That was devastating, and anyone else I've spoken to who's been through that- it's just horrific. You leave hospital with all your half-dead flowers, and no babies to put in the brand-new car seats, and no babies to put in the cots. (Jess)

Travel to and from the nursery after the mothers' discharge was exhausting. Postcaesarean mothers relied on family and friends to drive them and several regretted having to impose on others in this way. Interhospital transfers were times of considerable stress, as mothers strove to familiarize themselves with a new environment and renegotiate their role.

Then there was the hysteria when I had to leave them again. . . I just cried the whole way home. I was just frantic, on high alert the whole time. But trying to be polite, trying to be nice to the nurses. I didn't want any of them to be mean to them [the babies]. (Anne)

This concept of mothers 'playing the game' and needing to work to negotiate their place within the nursery has been described previously (Fenwick et al., 2008).

All mothers expressed breast milk, with durations from 5 weeks to 12 months. Most hated it but 'it was the only thing you could do for them'. Trying, and failing, to provide sufficient milk for multiple babies was demoralizing.

All were relieved to eventually stop expressing, however two mothers described healthcare providers making 'judgmental' comments.

**Life since discharge.** Seven mothers found life at home with multiple prematurely born newborns extremely difficult. Their babies' needs were relentless and physical exhaustion was without relief.

'I've never been so tired in my whole life. I never thought I'd sleep. I hated them some nights, I just thought, 'Shut UP!'" (Anne)

For some, this was before any special needs were apparent. Several mothers experienced legacies of their time in NICU: intense, almost phobic fear of infection, persistent perceptions of their multiples as vulnerable, and difficulty trusting anyone else to look after them.

'We were so utterly obsessed with them not getting sick- we just wouldn't let people anywhere near them. That was pretty awful.' (Kim)

'I really do struggle with leaving them with people. I think that comes from the fact that in hospital, I HAD to leave them, I had no control over that.' (Jill)

As time passed, social isolation, boredom, and sadness over their children's problems became more problematic. For developmentally discrepant twins, each milestone achieved by the non-disabled child highlighted the other's deficits:

I had to be happy for her crawling, when I'd just found out that her sister had cerebral palsy. So I actually did not cheer her on, when she started crawling. I hardly cheered her on when she started walking. And then I had incredible guilt about that. (Anne)

Conversely, when the delayed twin did reach a milestone:

When Justine started walking we were so focussed on it, so when she was taking the steps, we were crying and screaming and clapping. I couldn't find Allie, so I looked in their bedroom and she was standing in the dark with her hands over her eyes. It broke my heart to see her, at two years of age. (Anne)

With the early years normally being a time of rapid development, the opportunities for fresh heartbreak were many. Over time, the developmental gap between many multiples widened, heightening mothers' distress. The contrast was particularly painful when the twins were monozygotic (yet so clearly *not* 'identical'). Here, the discrepancy between what was and what could have been was not merely theoretical: it was visible in flesh and blood, taking the 'living loss' described as chronic sorrow (Roos, 2002) from the abstract to the concrete.

At the same time, Rachel's progressing and becoming more and more independent, and less actual care

**TABLE 1**  
Characteristics of Mothers and Multiples

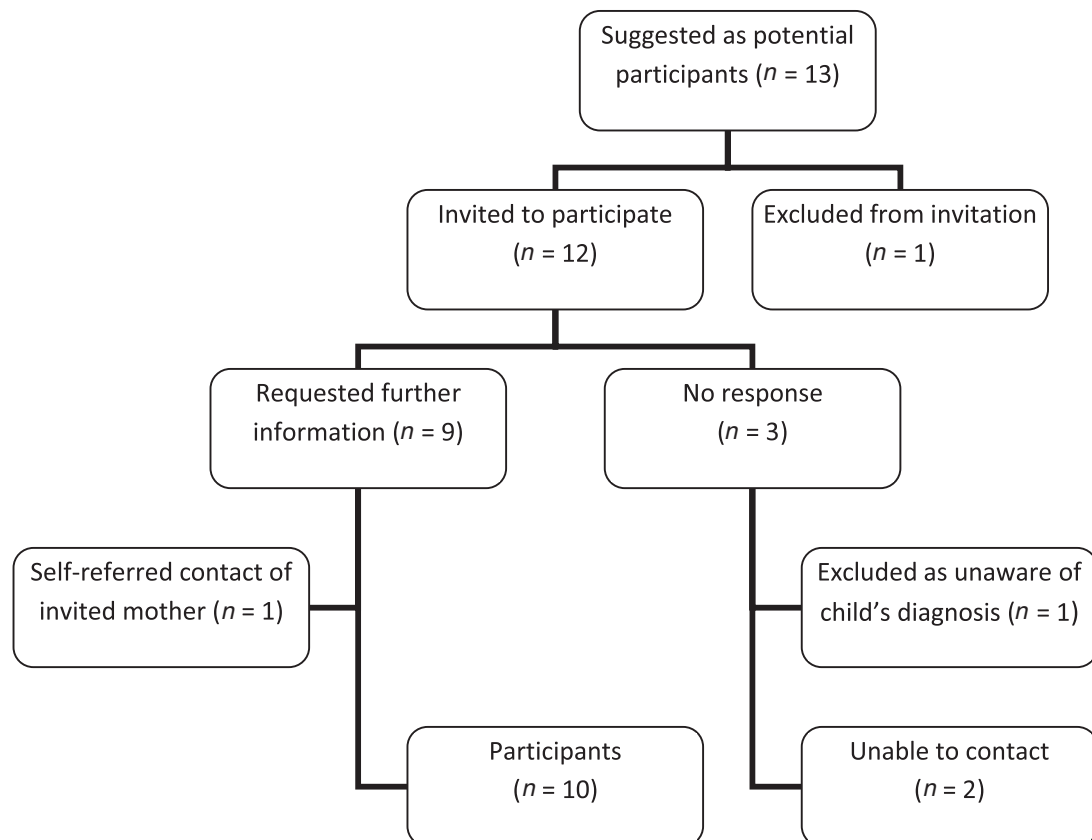
Characteristic	Description
Age range	Mid-20s to early 40s
Marital and domestic status	All married or in long-term opposite-sex partnerships, living with multiples' biological father
Ethnicity	All Australian-born, one of non-English speaking background
Place of residence	Five suburban, three outer metropolitan, two rural areas
Employment	All previously employed, one in part-time paid work at time of interview
Other children	Two mothers with a previous singleton, eight with multiples only. None with subsequent children
Method of conception of multiples	Six spontaneous, two in vitro fertilization (IVF), one ovulation induction medication, one spontaneous and IVF (fraternal twins resulting from single-embryo transfer cycle)
Plurality	Nine sets of twins, one set of triplets
Zygosity <sup>a</sup> of multiples	Seven dizygotic (fraternal), three monozygotic ('identical')
Chorionicity <sup>b</sup> and amnionicity <sup>c</sup> of monozygotic multiples	One dichorionic, two monochorionic. No monoamniotic gestations
Sex of multiples	Four different sex sets, six same-sex sets (four male, two female)
Gestation of multiples at birth	24 weeks 3 days to 33 weeks 6 days
Complication leading to premature birth	Five preterm premature rupture of membranes, two pre-eclampsia with intrauterine growth restriction, two idiopathic premature labor, one twin-to-twin transfusion syndrome
Mode of delivery	Six emergency caesarean, four vaginal (two spontaneous, two augmented)
Age of multiples	1 year 3 months (corrected for prematurity) to 5 years 11 months
Multiples concordant or discordant for special needs	Eight discordant (one with special needs, one without), two concordant (both/all have special needs)
Range of special needs <sup>d</sup>	Cerebral palsy (six children; one spastic quadriplegic, three spastic diplegic, two hemiplegic), developmental delay (five children), chronic lung disease (three children), gastrointestinal malformation (three children), oral aversion and/or tube feeding (three children), autism (one child)

Note: <sup>a</sup>Derived from one fertilized egg or two; 'type' of multiples.

<sup>b</sup>Number of placentas.

<sup>c</sup>Number of gestational sacs.

<sup>d</sup>Some children had more than one special need.

**FIGURE 1**  
Response to recruitment.

needed, whereas Lisa is still- what I do for her, is what you do for probably a six month old baby. Except this one weighs seventeen and a half kilos at the moment. (Jess)

Such ongoing sorrow differs materially from bereavement in multiple birth, where 'the grief seems to lessen in intensity over time' (Swanson et al, 2002).

The potential for a complicated response to a sibling's disability would seem magnified when that sibling happens to be a twin. As Bryan (2003) described, 'Jealousy in the early years followed later by guilt and an excessive burden of responsibility are common emotions of the unaffected twin.' The egocentricity of the developmentally normal preschooler was understood by these mothers, but that did not make the situation any less painful.

I didn't think it was fair on her [twin without a disability] to be schlepping around all these doctors and physios and the whole bit. . . I found that really hard too, I always felt like I was neglecting her. . . and I didn't like her feeling as if she's just been dumped off. Because in her little head, it's not like 'Oh, Mummy's going to the doctor, and poor Mummy and poor Lisa,' in her little mind, it's 'Well, I'm being dumped off again.' (Jess)

Balancing the care and therapy requirements of one child with the other's natural need for attention, presented an insoluble dilemma for several mothers.

When we confirmed Allie's diagnosis [mild hemiplegia] and told her she would be getting an AFO [ankle-foot orthosis] to wear like her sister's [dense hemiplegia] she started clapping and saying 'Hooray, I am getting a butterfly shoe!' I just wanted to cry at the fact that both my twins would be wearing them, but she was so happy because she wasn't going to be left out anymore. (Anne)

Two mothers related instances of their twins without disabilities being solicitous of their twin, to a degree characteristic of a much older child. As difficult as being an able-bodied twin must at times be, the multiple relationship also offers ample opportunity for development of empathy.

**Medical care, positives, and negatives.** Nine mothers had given birth to their multiples at the tertiary referral hospital through which recruitment was conducted. However, many interhospital transfers occurred, both before and after birth. Mothers and multiples had received care at 5 additional public and 4 private maternity and pediatric hospitals throughout metropolitan and rural Victoria.

Mothers' appraisals of their experiences of obstetric and neonatal healthcare shared similarities with previous reports from the singleton literature. Mothers valued care which was empathic and respectful.

They would ask me 'What do you think's going on with him? Is he the same, is this normal for him?' That's really empowering as a parent. For someone to really trust your opinion, and to make you feel like it counted. (Alice)

'We always felt like they really did care, about us and about our babies.' (Jess)

Most women reported some care which was experienced as callous, discourteous, or otherwise inappropriate. One mother spoke for several others when she made her observation of the medical system:

'It's frightening, it's scary, and most of the time, you feel like no one is listening. And it's a difficult system to weave your way around, and know where to go.' (Kim)

Mothers were particularly appreciative of care which took the multiple relationship into account. For example, 'bending' nursery rules to allow a less sick twin to be cared for beside his sicker twin in NICU, or (when side-by-side nursing was not possible) nurses communicating closely with each other and the mother to ensure coordination of care schedules, so the mother could provide care for both or all her babies. This did not always occur. One mother was very frustrated to find a nurse had given her medically unstable twin a rare bottle of expressed breast milk, while she was in the next room with his brother:

I got really angry, and I said 'Look, this is not good enough. I'm the mum. We've got a mum and a dad here who go home every night without their children. When you live this life, you can take away my bottle feeds. But you don't know what that's like.' (Jill)

**Impact of special needs.** Mothers of multiples with permanent disabilities described the devastation of learning of their child's (or children's) condition. Two mothers of young multiples diagnosed with cerebral palsy (one with hemiplegia, the other spastic diplegia) described their initial assumption that their children would be profoundly disabled and wheelchair-bound. Their distress was compounded by searching the Internet and being confronted by worst-case information. Clinicians' understandable reluctance to prognosticate regarding likely extent of disability prompted mothers to 'fill in the gaps' themselves.

'I did feel suicidal. . . I never thought we would laugh again, after diagnosis.' (Anne)

Mothers of multiples requiring ongoing management for sequelae of prematurity (for example, chronic lung disease, or feeding difficulties) were more likely to feel optimistic about the future than those with anticipated lifelong disabilities. Unsurprisingly, maternal distress increased with increasing severity of problems and greater actual care needs.

'It just shatters your whole world.' (Jess)



Serious self-reported maternal mental health problems were common, and included major depression, postnatal depression, post-traumatic stress disorder, and anxiety. However, such problems were not universal, and did not necessarily reflect the 'objective' extent of disability.

'It's physically exhausting, mentally exhausting constantly planning for it [disability] and accommodating it, and trying to work out how you can do everything, and still trying to balance it with Rachel.' (Jess)

For children with more severe disabilities, the paperwork required to access necessary services and equipment was a constant frustration.

I don't want to do all this! I don't have TIME to do all this! This is the time I should be spending with my family and doing stuff with my kids, and maybe doing therapy with Lisa, rather than writing out paperwork for bits of equipment! (Jess)

**Social supports.** Eight mothers described receiving tremendous support from their husbands/partners and extended family.

My husband and I try to be the yin and the yang, and boost each other up. I certainly don't know what I'd do if I was a single mum, I don't even know if I'd be here if I was a single mum, by now. (Jess)

None of the primary relationships of mothers in this study had dissolved since the birth of multiples, although all had experienced strain. This contrasts with previous reports of high prevalence of marital breakdown within multiple birth families (Spillman, 1992). The significant involvement of many fathers of multiples in infant care has been documented previously in academic and lay literature (Cooper, 2004; Flaherty & Damato, 2009; Simpson & Paviour, 1994) and was supported by this study.

For several mothers, their new circumstances (as mother of multiples with special needs) meant that old friendships were tested and found wanting.

'Your friends are basically useless; I think they're all so scared of the fact that your baby's sick.' (Kim)

Government-sponsored New Mothers Groups were almost universally unhelpful to these mothers:

'They were all perfect, term, singleton babies.' (Kim)

'Going to mothers group was hell. I just used to think, I feel like I'm driving somewhere, and I'm deliberately sticking a knife in my heart and turning it around.' (Anne)

Mothers of babies hospitalized at the same time frequently organized their own informal mothers groups; these were more helpful, allowing mutual support from the prematurity perspective.

Disability- and prematurity-specific support groups were variably helpful. Many mothers relied on online communication for support. Online peer support has been described previously as helpful for mothers in the workforce with young children (Hall & Irvine, 2009) and for carers of children with special healthcare needs (Baum, 2004). Online support may be particularly relevant to mothers of multiples with special needs, whose caregiving obligations may preclude physically leaving the home for support.

Australia's multiple birth peer support group was generally experienced by this group of mothers as unhelpful. Mothers felt conspicuous mixing with mothers of multiples without disabilities, and were saddened by the contrast with their own children:

'Their twins were all born at 37 weeks, you know. So we found we actually felt really out of place, and we've never been back.' (Jill)

'I did go. There was just no one there with disabilities, it just put me off.' (Nina)

I'm watching all these babies doing all these great things together, they're all progressing around a similar age, and I've got Justine lying on the floor, not moving. While Allie's keeping up, and I'm looking at her with the other twins, thinking, 'That's what you should be doing with your sister!' (Anne)

These sentiments echo the distress of bereaved mothers in Swanson and co-workers' 2002 study, when confronted with living twins; 'They . . . felt jealousy and envy (and occasionally bitterness) when they saw others with two or more multiples' (Swanson et al, 2002).

In De Vos and colleagues' study of twin families discordant for intellectual disability (De Vos et al., 2002), the authors noted that 'They [the mothers] missed talking with other parents in the same situation.' Mothers in the present study were likewise unable to find support that met all their needs (prematurity, special needs, *and* multiple birth).

'All I yearned for was other mums in the same situation.' (Nina)

**Multiple-specific concerns.** From availability of multiple NICU beds, to having babies in different locations within a hospital (or even in entirely different hospitals), mothers of premature multiples faced logistical difficulties in addition to managing their own physical recovery and providing for their infants' needs.

'And then there was the big drama that there were no NICU beds available. There was one. We needed two.' (Jill)

All mothers articulated or intimated that the natural state for their newborn multiples was for them (the infants) to be together. Mothers shared the expectation that their

multiples would be nursed together (in the same cot, or next to each other in separate cots) wherever possible.

‘To put them in the humidicrib together- I was so happy. I thought, ‘You’re in together!’ You know, it’s the first time they’ve been back together, and that’s what you want when you’re a twin mummy.’ (Anne)

Separation of infants (even to different sections of the same unit) created psychological conflict which was described by several as being physically painful, with mothers forced to choose whom of their infants they would spend time with. Feelings of guilt over this were common and persistent.

‘They were in different sections. So we had to choose who to visit first. That still upsets me. How was I meant to choose?’ (Anne)

‘I was running backwards and forwards. . . And that was really one of the hardest things for us, is that we’d miss out on cares with Adam ‘cos we’d be in with Tom, or vice versa.’ (Jill)

‘There’s always guilt associated with leaving one and going to the other.’ (Kim)

More problematic still was staggered discharge of multiples (taking one home before the other/s). Five mothers experienced staggered discharge, with gaps ranging from 2 weeks to 6 months.

Bringing Rachel home [first] was really weird. We felt bad for both of them, we felt bad that they were separated, and felt really awful that they were separated from birth, after being inside me together- we felt like that bond had been broken. (Jess)

‘It just felt wrong, to bring one home without the other.’ (Jill)

Mothers used terminology of ‘waiting’ and ‘biding time’ until their babies were reunited at home.

‘We took Yvette home, and we had another week and a half. It actually seemed like months before we got Jack home. . . I never really got into a routine with it, never got comfortable with it.’ (Kim)

Of the five mothers experiencing staggered discharge, none indicated she had preferentially bonded with the infant first discharged. These babies were required to accommodate the mother spending time with the hospitalized infant. In two instances, the mothers suggested they were preoccupied with the infant still in hospital.

I didn’t want Joseph [discharged twin] to get anything extra out of me as a mum, than Peter [hospitalized twin] could. . . For those two months when I had one in hospital, one at home, every day I went in to see Peter. Every second day, Joseph would come in with me, and every other day mum would look after Joseph on her own. (Alice)

This is in contrast to previous reports suggesting mothers preferentially bond with the twin first discharged (Hay, 1999, on data collected in the 1970s; Linney, 1980). Staggered discharge, while sometimes unavoidable, increased the strain on mothers, by combining the demands of a prematurely born newborn at home with the anxiety of a child still in hospital.

One mother, whose twins were discharged four months apart, described the homecoming of her second twin as ‘The biggest day of my life.’ Another mother (with two months’ gap) said it was ‘so nice to be home as a family’.

‘That was great. It was like, ‘Yep, they were- they ARE twins.’ (Cath)

After discharge, ferrying multiple children to medical appointments became a challenge. Mothers described the difficulty of distracting multiple children during lengthy waiting room periods, the impracticality of getting a twin pram *into* a consulting room, and the impossibility of concentrating on therapy or advice while supervising multiple children:

‘This is very difficult for me! I’m sweating, I’m trying to make sure one’s not distressed, while getting her leg yanked apart, while the other one knows she’s gonna get her leg yanked apart.’ (Anne)

Mothers were resourceful in their efforts to ease the strain:

‘I’ve got a thing where if I’ve got the three of them with me, I always sit near the receptionist, and I let them make as much noise as possible, so they sort of creep me up. Because when they were younger, I just remember, it would be so hard.’ (Hana)

## Synthesis

To the authors’ knowledge, this study represents the first attempt to document and interpret the experiences of a group of mothers of young multiples with diverse special needs. Although there were some differences in outlook and interpretations, their stories were remarkably similar and some generalizations may be made.

The theme of loss ran prominently through the stories: loss of the imagined single baby and opportunities thereby denied, loss of the opportunity to mother her twins as she wanted to, and for those discordant for disability, sorrow over her children’s loss of a ‘normal’ twin relationship. Many mothers expressed feelings of guilt, which were no less powerful because their circumstances were unavoidable. From a self-perceived ‘failure’ to protect her babies *in utero*, to the inability to provide sufficient breast milk, to causing one child to ‘miss out’ by spending time with the other (even when this was on medical grounds), the burden of guilt weighed heavily on many. A sense of physical and social isolation was common, and it was clear that formal community supports were inadequate. Those that were used addressed some, but not all, of the mothers’ needs; what was lacking was the opportunity for contact with someone

who really understood having multiples *and* ex-premature infants *and* children with special needs.

Mothers' expectations regarding their multiples of togetherness and, to an extent, 'sameness' were disturbed by the event of premature multiple birth and subsequent diagnosis of special needs, as were their own aspirations to fairness in mothering. With such psychological demands, added to a heavy physical workload and frequently inadequate support, it is not surprising that many mothers experienced compromised mental health.

This study attests to the complexity of the relationships between a mother and each of her multiple birth children, and to a lesser extent, between the children themselves. Mothers clearly expressed concern over difficulties facing their children, arising from their multiple status.

Further work is needed to bring understanding of maternal attachment in the context of multiple birth in line with mothers' experiences. Most work on mother-to-twin 'bonding' focusing on maternal preference is 30 years old. The mother-child-child relationship deserves renewed exploration, in the light of the passage of time, changes in neonatal and parenting practices, and the implications for families of professionals' assumption that a mother cannot 'bond' with two or more babies with equal success.

We believe this study is the first to introduce the concept of disenfranchised grief to the experience of mothering multiple birth children with disabilities. Similarly, the authors are unaware of prior description of depersonalization following multiple birth, or use of the term 'chronic sorrow' in the context of mothers of multiple birth children with disabilities.

The study suggests the need for further research into factors predisposing mothers to, and protecting them from, lasting mental health problems. Research on the impact of multiple birth on fathers is in its infancy, but likewise merits serious investment. Direct inquiry involving multiple birth children themselves, and evaluation of longer term implications for multiples with and without disabilities is needed.

As a qualitative study with 10 participants, findings of this study are of limited generalizability. However, there were many similarities between the mothers' accounts and it is reasonable to suppose their experiences may be replicated elsewhere. This study may offer some insight into the possible challenges facing mothers under similar circumstances. Formulation of policies and procedures to reduce unnecessary stress, and alleviate unavoidable distress for mothers of multiple birth children is warranted. With this in mind, a larger scale, quantitative exploration of factors affecting quality of life of parents of multiple birth children, particularly those with special needs, is required.

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