

Multiple perspectives:

What support do multiple birth families need to live happy and healthy lives?



This discussion paper is a compilation of case studies and opinions collected from Twins Research Australia's collaborators. It provides a wide-ranging overview of issues and challenges for families and health professionals during pregnancy, birth and the early life of twins and multiples. Its aim is to initiate further discussions and explorations, and it provides recommendations for research, education, policy and practice.

Acknowledgements

This paper is a collaboration of Twins Research Australia, the Twins and Multiple Births Association (TAMBA – UK), the Australian Multiple Birth Association (AMBA) and the International Council of Multiple Birth Organisations (ICOMBO).

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Acronyms and abbreviations

AMBA	Australian Multiple Birth Association
DZ	Dizygotic
ICOMBO	International Council of Multiple Birth Organisations
IVF	In vitro fertilisation
MCaFHN	Maternal child and family health nurse
MZ	Monozygotic
NICE	National Institute for Health and Care Excellence
NICU	Neonatal Intensive Care
TAMBA	Twins and Multiple Births Association, UK
TTTS	Twin–twin transfusion syndrome
UK	United Kingdom

Executive summary

The rate of multiple births (twins, triplets and above) has continued to rise worldwide over the past three decades. These families face significant challenges from pregnancy through birth and the first five years of their babies' lives. However there is little existing evidence-based knowledge of these issues leading to an under-estimation of the struggles of multiple-birth families and inadequate support for them.

This first-ever international discussion paper is a collaboration of multiple-birth agencies: Twins Research Australia, Twins and Multiple Births Association (UK), Australian Multiple Birth Association, and the International Council of Multiple Birth Organisations. This collaboration has brought together the experience and expertise of the many stakeholders in multiple-birth healthcare including parents, community organisations, health professionals, researchers and educators.

This discussion paper is a compilation of case studies and opinions collected from these key stakeholders. It aims to identify the difficulties facing multiple-birth babies and their families, the gaps in our current knowledge, and the way forward to address these gaps.

Some of the increased pregnancy and birth risks facing multiple-birth families are:

- Women with multiple pregnancies are more prone to pregnancy complications, for example anaemia, bleeding, high blood pressure and diabetes occur two to three times more frequently in twin pregnancies and even higher in triplet pregnancies.
- The rate of babies dying during pregnancy or in the first month after delivery is at least three times higher in twins and higher in triplet pregnancies.
- Cerebral palsy is 20 times more common in triplets.
- The risk of premature birth before 28 weeks is 10 times higher in twins and 30 times higher in triplets.

Ongoing difficulties being faced by multiple-birth families include:

- Lack of awareness of the greater parenting stress associated with multiple births, particularly where one or more baby has special needs.
- Significantly increased family financial stress due to increased medical and other costs and less earning capacity as a result of increased time demands for child caring.
- Increased risk of social isolation, anxiety and depression among multiple-birth mothers.
- Inadequate bereavement support when one or more babies do not survive.
- Significant variability in the quality of medical and health advice relating to multiple pregnancies, births and child development.

Other difficulties in first five years of infants' lives:

- Possible developmental delays e.g. speech, language, learning, social and cognitive.
- Unique educational considerations e.g. age of school entry; to separate or not in the classroom.
- Possible special needs and disability with one or more infants.

The report provides recommendations for action in the areas of research, education, policy and practice. It has identified three priority areas for urgent action:

- The development of policies to tackle the financial disadvantage experienced by multiple-birth families;
- The need for further research to more precisely understand the unique physical and mental health concerns of these families; and
- Improved education for health professionals and parents.

The collaborators' next steps are to prioritise recommendations and actions, seek research funding, and engage with government, health services, education providers, researchers and research funding organisations.

In taking these steps, it is hoped to support health services and professionals to better meet the needs of multiple-birth families and to provide much improved outcomes for them.

Background

Twins, multiples and their families face significant challenges arising from twin and multiple pregnancies, births and the first five years of life. These include higher rates of pregnancy-related complications, preterm and low-birthweight babies, and mental conditions such as post-partum depression and parental stress that can put long-term pressure on the whole family. In addition, ongoing difficulties with multiples' health and development can result in a larger financial burden for parents of multiples than parents of singletons. Challenges include lower than average income, material deprivation and a slower return to work for mothers of twins and multiples. Misunderstandings of zygosity assignment and its emotional impact on multiples and their families have also been stressed in the literature. However, there is little existing evidence-based knowledge of these issues in the Australian context, leading to an underestimation of the struggles of these families.

Introduction

A first-ever public forum in Melbourne, hosted by Twins Research Australia, the Twins and Multiple Births Association (TAMBA – UK), the Australian Multiple Birth Association (AMBA) and the International Council of Multiple Birth Organisations (ICOMBO), brought together the many stakeholders in multiple-birth care to discuss ways to improve the health and wellbeing of twins, higher-order multiples and their families.

This was the beginning of an initiative to shape public conversations, practice and policymaking to address the social and health inequalities of twin and multiple families, while providing a space for collective learning and sharing of knowledge specific to the Australian context.

To move the conversation forward, a discussion paper has been created to reflect the diversity of perspectives that emerged from the forum – from researchers, health professionals, service providers, community organisations, twins and their families. It is a compilation of case studies and opinions collected from Twins Research Australia's collaborators that aims to provide a narrative of the issues and challenges of twin families and health professionals during pregnancy, birth and the early life of twins and multiples.

Our aim is to outline the knowledge that currently exists, show where the gaps are, and explore the steps needed to address these gaps. This document will be used to formulate recommendations for raising awareness of the needs, identify future research and influence change to policy and practice. Twins Research Australia thanks our many collaborators who made this discussion paper possible, including TAMBA, AMBA, ICOMBO, health professionals, researchers, and most importantly, twins, multiples and their families.

Chapter One: Challenges in the clinical setting



1.1 Higher complication rates of twins and multiple pregnancies

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Multiple births have increased substantially over the last 30 years. In 1986, 2636 sets of twins and 52 sets of triplets were born in Australia, but 4497 sets of twins and 81 sets of triplets in 2016. Other than natural increase due to population growth, the rise in twin numbers is primarily attributable to increased rates of assisted reproductive technology and, to a lesser extent, women having their babies later in life when twins become more likely to occur spontaneously.

Women with a multiple pregnancy are more prone to virtually all of the complications of pregnancy. Some of the complications that are traditionally listed as “minor” can vary from being quite troublesome to very serious. Nausea and vomiting in pregnancy, tiredness, constipation, haemorrhoids, frequent urination, varicose veins, heartburn and leg cramps all occur more frequently.

More serious medical complications can pose problems to both mother and baby. Anaemia, bleeding, high blood pressure and diabetes all occur two to three times more frequently in twin pregnancies, and even more frequently in triplet and higher-order pregnancies.

Twins who share a single placenta are at increased risk of specific conditions, primarily related to unequal sharing of placental blood flow; these include twin–twin transfusion syndrome and selective fetal growth restriction. They also have a higher rate of fetal anomalies. Additionally, in very rare cases, twins can share a single amniotic sac and their cords become entangled or the twins may be conjoined.

The perinatal mortality rate, that is, the rate of twins dying during pregnancy or the first month after delivery, is at least three times higher in twins and up to ten times higher in triplet pregnancies. Cerebral palsy is four times more frequent in twins and up to 20 times more common in triplet pregnancies.

The major concern with multiple pregnancies, and the cause of many neonatal problems, is the increased risk of premature birth. Approximately 5% of twins and 15% of triplets are born before 28 weeks' gestation, compared to 0.5% of single pregnancies. Problems with breathing, feeding, keeping warm, infections, speech and reading difficulties, visual disturbance, behavioural disorders and learning disorders may be consequences of being born too early.

The prevention of premature birth in twins is a major focus for obstetricians providing care for women with a multiple pregnancy.

Interventions including cervical sutures, vaginal pessaries, bed rest and medical therapies have all been tried with limited success. Further research into the prevention of preterm birth in multiple pregnancies is essential to find therapeutic options that can reduce the risk of significant long-term adverse outcomes.

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1.2 Higher complication rates of twins and multiples: A UK perspective

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A multiple pregnancy is associated with increased perinatal mortality and morbidity for both mother and babies. Multiple pregnancies are affected by higher rates of complications – such as anaemia, hyperemesis gravidarum, pre-eclampsia, gestational diabetes, obstetric cholestasis and postnatal illness – than singleton pregnancies. These pregnancies have higher rates of stillbirth and neonatal death. Preterm birth is also considerably more frequent in twin than singleton pregnancies, occurring in at least 50%, with twins facing six times the risk of cerebral palsy. Other risks to the babies include fetal growth discordance and congenital abnormalities. Those babies that share the same placenta have additional risks, such as twin–twin transfusion syndrome (TTTS) and twin anaemia polycythaemia sequences, a form of TTTS.

High-quality effective care provided by a nominated multidisciplinary team is essential. The benefits of providing continuity of care for multiple pregnancies are well documented.

The team of health professionals caring for multiples should be specialised in caring for multiples. Unfortunately, standards of care have been found to be inconsistent and too varied in outcome.

Studies have shown that a dedicated, specialised multidisciplinary approach is fundamental to the delivery of high-quality care for women with a multiple pregnancy and contributes to improved outcomes for both mother and babies.

The National Institute for Health and Care Excellence (NICE) recommends that women with a multiple pregnancy are cared for by a nominated multidisciplinary team which includes a specialist midwife. At present, the evidence is sparse; one study recommends the midwife's involvement to improve maternal psychological outcomes. Furthermore, a Cochrane review stated that there is currently insufficient evidence to establish the effectiveness of specialised antenatal clinics for women with a multiple pregnancy compared with standard care. Evidence suggests that antenatal care in the UK provided by maternity units which aligns with national clinical guidance has the potential to reduce the clinical risks associated with fetal compromise and produce better outcomes for mother and babies.

Policymakers must ensure that NICE Guidelines are embedded into current practice. Conducting more research into the effectiveness of continuity of care by multidisciplinary teams and the benefits of specialised twins' clinics is recommended.

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1.3 Diagnosing multiples

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Contrary to popular belief, most multiple pregnancies are spontaneous and unexpected. Several studies have shown that a diagnosis of multiple pregnancy (including one conceived using assisted reproductive techniques such as in vitro fertilisation –IVF) can be a source of considerable distress for prospective parents. Particularly for first-time mothers, a multiple pregnancy may in fact represent the loss of a desired intimate, one-to-one relationship with an imagined (single) baby.

Health professionals diagnosing multiple pregnancy may be unaware of the wide range of possible reactions to the news, because parents can be reluctant to share their feelings openly for fear of being judged negatively.

For parents who have struggled with infertility, a multiple pregnancy may be perceived by others (sometimes by themselves) as providing them with an “instant family”. There are few opportunities for these parents to publicly acknowledge any ambivalence they may feel about the diagnosis of multiples, because of the unspoken assumption that they should consider themselves lucky to be pregnant at all. Prospective parents may therefore experience disenfranchised grief – “when they incur a loss that is not or cannot be openly acknowledged, socially sanctioned or publicly mourned” (Doka, 1989). The impact of such grief on subsequent adaptation to parenting is not known.



Many health care providers (including some obstetricians, midwives and sonographers) fail to appreciate that in one third of monozygotic (identical) twin gestations, there are two placentas – thus presence of two placentas does not automatically confirm a fraternal pregnancy. In fact, 10% of twins with two placentas are identical (the proportion rises to 20% if the twins are of the same sex). Incorrectly assigning zygosity may have social and medical consequences. Early (first trimester) and accurate diagnosis of chorionicity (number of placentas) is likewise extremely important, because it guides subsequent obstetric decision-making (for example, frequency of monitoring and optimal timing of birth). Multiple-birth families do not currently have ready access to testing to ascertain their children’s zygosity, except at considerable personal expense.

Reference

Doka KJ (Ed.) *Disenfranchised grief: recognizing hidden sorrow*. Lexington, MA: Lexington Books, 1989.

1.4 Parental and professional knowledge of twin identity

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Zygosity refers to the genetic similarity within twin pairs. Monozygotic (MZ) twins originate when a single sperm fertilises a single egg; they are essentially genetically identical. Dizygotic (DZ) twins originate when separate eggs are fertilised by separate sperm; they are as genetically similar as any brothers or sisters. MZ twins are always the same sex. DZ twins can be the same or of a different sex.

DZ pairs are dichorionic – that is, each twin has its own placenta. MZ twins may also each have their own placenta (in about a third of cases) or share the same placenta (monochorionic, in about two thirds of cases).

During the first trimester of pregnancy, ultrasound scans can be used to determine chorionicity. Chorionicity can also be determined by examining placentas at birth. In the second trimester, when sex can be determined, different-sex twins must be DZ. However, without a genetic test, dichorionic same-sex twins cannot be assigned a zygosity. If such twins were routinely tested for zygosity at birth, and this information conveyed to parents and entered into medical records, all twins would know their genetic identity. However, such testing is very rare. As a result, up to a third of twins are unsure or have been misinformed about their zygosity (Cutler et al., 2015). This is far from ideal because such knowledge is important to twin families for the reasons provided below.

If one twin is diagnosed with a medical disorder, the likelihood that the other will develop the same disorder is higher in MZ pairs than in DZ pairs. Early detection of a condition in the second twin may increase the chance of successful treatment. Monozygosity also guarantees tissue compatibility if a transplant is required.

With accurate zygosity knowledge, twins and their families can also confidently answer the inevitable zygosity questions from friends and strangers. In addition, the likelihood of a mother giving birth to a second set of twins is higher in mothers of DZ twins, and this knowledge is obviously important for family planning purposes.

Twins report that zygosity knowledge helps define their social relationship and provides peace of mind (Cutler et al., 2015).

For these reasons, twins and their families believe that knowledge of genetic identity is a basic human right (ICOMBO, 2015). We agree and recommend universal, affordable zygosity recording and testing (if necessary) for all twins and higher order multiples, ideally at birth.

We also recommend better training for parents and clinicians to make them aware of zygosity and its many implications.

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International Council of Multiple Birth Organisations (ICOMBO), *Declaration of rights and statement of needs of twins and higher order multiples*, 2014. <http://icombo.org/wp-content/uploads/2010/11/Declaration-of-Rights-2014.pdf>

1.5 Loss of babies from multiple births

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Bereavement due to loss of a baby from a multiple birth is unique and complex. Parents may feel they have lost more than their child(ren), but also special status as a multiples parent.

In supporting bereaved multiple birth families, there is a responsibility to understand their specific needs, which professionals working with such families must have opportunities to learn about within initial training or continuing professional development.

Bereaved multiples parents benefit from specialist support; a “one size fits all” approach to care overlooks the multiple aspect.

Multiple-birth families can experience bereavement in various ways. If a baby survives, parents may struggle to balance grief with caring for and bonding with this child. Selective reduction (the practice of reducing the number of fetuses in a multiple pregnancy) also brings conflicting emotions. A death early in pregnancy is very different from one in infancy. Research to improve understanding of the best ways of supporting parents in each situation must be done sensitively.

The care bereaved families receive affects how they feel about their loss in the long term. Research shows common concerns include:

- not knowing what to expect after loss (during birth, seeing their deceased child, going home)
- needing help to coordinate support
- mental health issues
- making informed choices about interacting with and/or remembering their child
- bonding with a surviving baby
- not receiving adequate understanding or support at work.

Poor communication between professionals and insensitive comments from them are particular concerns. Conversely, parents are appreciative when professionals use their babies’ names, recognise the challenges of raising a surviving baby, ask about or attend funerals, give parents chances to talk, and help them to consider funerals or memorial rituals outside the ward, including for reductions, with opportunity to bury multiples together (Pector, 2004).

It is crucial that parents are invited to shape best practice, and that all health professionals who meet bereaved families of multiples are trained to treat them with care and dignity.

Reference

Pector E. How bereaved multiple-birth parents cope with hospitalization, homecoming, disposition for deceased and attachment to survivors. *Journal of Perinatology* 2004; 24(11):714-722.

1.6 Fetal loss and bereavement

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Perinatal loss of twins and higher-order multiples is much more common than for singletons, with twins at approximately seven times and higher-order multiples at over 18 times the risk. This excess risk is not solely due to greater likelihood of preterm birth and low birth weight; even among babies born weighing over 2.5kg, twins are over-represented among neonatal deaths.

Parents who experience antenatal bereavement may grieve their loss whilst continuing a pregnancy in the hope of benefiting the survivor/s. Research on this situation is very limited, but well-meaning advice from health care personnel to “focus on the survivor/s” has been shown to interfere with parents’ opportunities to grieve. The survival of one child does not in any way make up for the one/s who were lost. An awareness initiative developed in the UK by parents of identical twins, one of whom died soon after birth, may be helpful in these circumstances. A purple butterfly sticker is placed on the cot/s of surviving infants who were part of a multiple pregnancy which involved a loss. This subtle indicator reduces risk of hurtful comments from nursery visitors (such as “You’re lucky you don’t have twins!”), acknowledges the survivor’s twin or triplet status, and opens up opportunities for supportive interactions. The Australian Multiple Birth Association (AMBA) has introduced this postnatal initiative in Australia.

Care of bereaved families must allow for the reality of elevated risk of disability among surviving child/ren (particularly if multiples shared a placenta, in which case the demise of one fetus may have serious consequences for the other). Recommendations exist for the monitoring of survivors during pregnancy, but these may not be widely known. Valuable peer support resources for bereavement care of families of multiples are available (including from AMBA), but consideration should be given to supplementing these with evidence-based measures. Care of bereaved parents of twins must be ongoing; recent research demonstrates that bereaved mothers of twins are three times more likely to be depressed at five years than mothers of singletons.

In the multiple birth context, standard practices of preserving mementos of the deceased infant (such as photographs, footprints or locks of hair) are important not only for the parents, but also potentially for surviving co-multiple/s. Preservation of additional sets of mementos for the future benefit of surviving co-multiples should be considered carefully.

Multiple conception is considerably more common than multiple birth. An estimated 12% of pregnancies conceived are multiples, but in only 2% are twins delivered. The mechanism by which a gestation initially identified as multiple is reduced to single is termed the “vanishing twin phenomenon” (a somewhat misleading term, because the conceptus does not usually vanish, it becomes less apparent over time).

With the reality of increasingly early ultrasound diagnoses of multiple pregnancy (including following dual embryo transfer with IVF), the number of women experiencing the vanishing twin phenomenon has increased.

In pragmatic terms, such early losses are expected biological outcomes, but it is unknown to what extent they affect women’s adaptations to pregnancy or experiences of motherhood. Whilst the physical implications of a vanishing twin for pregnancy outcomes have been explored, no studies have examined the psychological effects on parents of an early loss of expected twins, or for the children who grow up in this context.

1.7 Key developmental delays: speech, language, cognitive capacity

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It is well documented that babies born prematurely with a low birth rate are at increased risk of having special needs (Costello-Harris and Segal, 2018). Twins, triplets and other multiples are more likely to be born prematurely. Fewer than half of twins are delivered after 37 weeks and only 1.5% of triplets are born after 37 weeks (NICE, 2011). In addition, congenital anomalies, growth restriction and the unique stresses that multiples can experience during pregnancy can put them at increased risk of special needs.

Special needs in twins and multiples are very diverse. Previous research show that multiples are at increased risk of cerebral palsy, one study showing a fourfold increase for twins over the general population prevalence (Sutcliffe and Derom, 2006). Language and speech delays, behaviour issues and developmental delays are all more prevalent in multiples.

To date there has been very little research focused on the health and social needs of the mother or caregiver of twins. However, there is evidence that multiple-birth families with children with special needs experience unique diagnostic difficulties and resource challenges (Costello-Harris, 2018). Parents of multiples experience greater parenting stress, and if one or more children has special needs this stress is exacerbated significantly. Furthermore, families with multiples are under greater financial pressure, which causes additional strain.

Further research is required to show the most effective ways to support families with multiples. With the rate of multiple births continuing to rise worldwide, this issue isn't going away. Greater awareness among both health professionals and professional bodies is also needed.



There are lots of resources for special needs families, but it's difficult for families of multiples to access this information due to the added stress and lack of time available to them.

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1.8 Special needs and disability among multiples

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Multiple-birth children are at increased risk of disability, due in part to increased risk of premature birth. Congenital malformations (such as spina bifida, club foot or heart defects) are more common, as are developmental difficulties including attention deficit hyperactivity disorder (ADHD), language disorders (including speech delay) and coordination problems (developmental coordination disorder, dyspraxia).

Cerebral palsy (a disorder of movement and posture due to damage to the developing brain) occurs in 0.59% of twins surviving pregnancy and the newborn period (1 in 170). In contrast, 0.15% of singletons have cerebral palsy (1 in 667). Overall, twins have between a four and tenfold increased risk of cerebral palsy. One in 85 twin pairs includes a child with cerebral palsy, and for approximately one in eight families with a twin with cerebral palsy, the other twin will also have cerebral palsy. Patterns of cerebral palsy differ, with two thirds of twins having spastic bilateral cerebral palsy (affecting both sides of the body) but less than half of singletons. Further research is needed to clarify the pathways contributing to cerebral palsy in twins, because they may be different to mechanisms in singletons.

Families of twins with disabilities have disclosed that community supports provided to developmentally typical children (including twin-specific peer support playgroups) often fail to meet their needs.

Mothers have reported feeling conspicuous when mixing with families of multiples without disabilities, and being saddened by the stark contrast with their own children. Careful consideration must be given to how to best support these families, who are particularly vulnerable to experiencing social isolation.

Research into the normal development of multiple birth children is lacking. Simply being a twin should not be accepted as an explanation for developmental delay; multiple birth might contribute to delays, but attributing delays to twinship (and not looking any further) means that some twins miss out on important diagnoses and supports. Young multiples need ample opportunities for one-on-one interactions with fluent language speakers. If their only conversation partner is their twin (who is also mispronouncing words, using the same limited vocabulary and making similar mistakes with grammar), young twins can reinforce each other's incorrect speech.

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Chapter Two: Improving the parents' experience



2.1 Lack of awareness of appropriate care for pregnancy and delivery

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Multiple birth pregnancies are high-risk pregnancies for several reasons. Conditions such as anaemia, pre-eclampsia and gestational diabetes are more common in multiple pregnancies. Other complications arise when the mother is expecting multiples, and whilst these complications are rare, they can have devastating consequences for the family. Twin–twin transfusion syndrome may occur when the multiples share a placenta; monochorionic (shared placenta) and monoamniotic (shared amniotic sac) twin and triplet pregnancies are relatively rare, but they have a high risk of adverse pregnancy outcomes.

Specialised medical personnel should monitor multiple pregnancies carefully to determine chorionicity and perform appropriate interventions if complications arise.

Anecdotal evidence shows that expectant parents receive a wide variety of medical experiences during their multiple pregnancy. These parents often resort to online forums to seek opinions and advice from other parents of multiples. Some expectant mothers receive their antenatal care from a midwife or doctor who is not skilled or experienced with multiple births. This can lead to inappropriate information being given to the mother about issues such as the amount of rest she requires and the ideal time of delivery. Some expectant mothers expect to deliver their babies at close to 40 weeks, even though research clearly shows that delivery should occur by 37 weeks.

In some countries, such as Australia and Canada, families may live several hundred kilometres from specialised care. They need to rely on a local medical team for the initial stages of the pregnancy and then transfer to a major centre for the later stages of the pregnancy and the delivery. For these families, it is imperative that the local medical team is well informed about best practice during pregnancy and is willing (and able) to liaise with specialists in major centres if complications arise.

2.2 Early parenting education and support

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Parents of multiple-birth children lack access to early parenting education that is specific to their needs. The case for additional parenting education and for government investment in practical supports for multiple-birth families, particularly in the early months, has been argued repeatedly for decades. The intense demands of caring for multiple infants, who are more likely to be premature and to have additional needs, limit parents' ability to access resources which may protect their mental health and promote their wellbeing. Parents of multiples have restricted opportunities to interact with other parents in similar circumstances. Studies have shown that existing education and supports provided to new parents (such as first-time parent groups and maternal and child health nursing services) do not necessarily meet the needs of parents of multiples.

Social isolation and perceived lack of support (both practical and emotional) is a strong predictor of depression in mothers of twins.

Mothers of multiples have reported feeling out of place among government-sponsored first-time parent groups (particularly when allowance is not made for twins' prematurity). Families for whom multiples are not their firstborn are ineligible to participate. Families from culturally and linguistically diverse backgrounds, and those whose children have disabilities, may particularly struggle to access appropriate support.

Typical advice on infant care (e.g. feeding on demand) and self-care ("rest when the baby rests") is usually inapplicable or unachievable for parents of multiples. Parents may only discover specialised techniques (such as the football hold for breastfeeding) by trial and error, and experience considerable anxiety over normal variations in development between their twins. Access to such practical advice is highly variable, and depends on parents actively seeking out resources (such as online parenting forums or specialist books) at a time when they are most vulnerable and least likely to be able to effectively find help.



There is a pressing unmet need for structured, multiple-specific early parenting education programs, and for adequately funded resources for parents of young multiples, to cater to their unique challenges.

2.3 The need for standardised antenatal parent education

Monica Rankin

International Council of Multiple Birth Organisations (ICOMBO)

It is highly recommended that babies from multiple birth pregnancies are delivered by 37 weeks, or earlier if there are specific issues with the babies. The average gestation for triplets is around 33 weeks and around 36 weeks for twins. Many twins are born well before 36 weeks, and often the parents are very surprised at the early delivery.

..... **Many parents appear totally unaware of the potential complications of a twin pregnancy.**

They expect that life will remain relatively unchanged until their babies arrive on schedule at 38 weeks. When these babies arrive early, perhaps as early as 26–28 weeks, they may be very ill and require lots of care. The parents feel at a loss as to how to cope with the situation; they have not been prepared for the possibility of having tiny, sick babies that will require hospitalisation for some time. In conversation with parents, it is obvious that most parents are ill-prepared for their newborns to spend time in hospital after the mother is discharged. It would be beneficial if antenatal education prepared the parents for this outcome. Many parents of multiples are informed that their babies may be hospitalised for longer than the mother, but it seems that they are not prepared for the emotional rollercoaster that the situation creates.

It is well documented that multiple pregnancies are high risk. Anecdotal evidence indicates that some parents are totally unaware of many of the risks, while others are so well informed that they have very high anxiety levels. Many people now resort to “Doctor Google” whenever they are presented with a medical problem; this can give them excellent information, but also information that is not appropriate to their situation. They often panic about possible scenarios that may not be relevant to them.

Standardised guidelines for antenatal care would ensure that all expectant parents of multiples receive accurate, up-to-date information that is relevant to them. They would know what to expect when and to trust that this information is correct and relevant to them.

2.4 Women’s experiences of high-risk and uncomplicated multiple pregnancies

Christie Bolch

Murdoch Children’s Research Institute, The Royal Children’s Hospital

Although all multiple pregnancies are considered to be high risk, most are relatively uncomplicated. Studies of high-risk obstetric populations (which did not specifically target mothers of multiples) find that antenatal anxiety and depressive symptoms are common, and that antenatal poor mental health predicts postnatal difficulties. Several studies consider the pregnancy experiences of women who have undergone multifetal pregnancy reduction (selective termination of one or more fetuses),

which differ fundamentally from uncomplicated multiple pregnancies. No qualitative studies to date consider the experiences of women who have relatively uncomplicated multiple pregnancies, nor women's experiences of complicated multiple pregnancies.

Even uncomplicated multiple pregnancies are accompanied by more frequent monitoring, appointments and investigations (such as internal ultrasound monitoring of cervical length, which some women may find intrusive) and greater uncertainty of the outcome. Mothers of multiples have been shown to experience greater "minor" discomforts of pregnancy and poorer physical health.

Providers of care to women expecting multiples should be alert to the greater physical stresses these women may bear, and encourage self-care and early recognition of ante- or postnatal mood disturbance.

Multiple pregnancy is invariably associated with significant changes to a woman's body. Not infrequently, permanent post-birth changes occur, such as stretch marks, breast changes or overhanging abdominal skin. The impact of such a dramatic transformation on one's sense of bodily integrity, self-esteem and wellbeing are unknown. The potential for body dissatisfaction to adversely affect the mental health of mothers of multiples has not been explored to date.

Health care workers outside major hospitals need better awareness of specific risks to multiple pregnancies with a shared placenta. For example, 10–15% of such pregnancies are affected by twin–twin transfusion syndrome (TTTS), which carries a near-certain risk of fetal death if untreated. Although detailed guidelines for surveillance of these pregnancies are available they are not always followed. This is concerning as failure to diagnose a shared placenta and/or TTTS has been shown to result in significantly poorer outcomes for infants and mothers.

2.5 Women's experiences of multiple childbirth

Christie Bolch

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Two thirds of Australian twins – and almost all triplets – are born by caesarean section, compared with a third of all singletons. Surgical birth has been shown to be associated with decreased maternal sleep and increased interruptions to sleep in the first week after birth, and a longer recovery period (4–6 weeks, compared with 1–2 weeks for a vaginal birth). A review of randomised controlled studies of multiple childbirth found that of women who planned vaginal birth for their twins, 43% required caesarean for at least one twin. Mothers of twins who gave birth vaginally were more satisfied with their childbirth experiences than those who gave birth by caesarean section.

Surgical birth and use of obstetric interventions (including instrumental delivery – vacuum extraction or forceps) have been shown to be associated with increased risk of adverse psychological effects (including post-traumatic stress disorder) in first-time mothers of singletons. However, these associations are not consistent across studies, and their applicability to the multiple birth setting is unknown. Research evidence about women's experiences of multiple childbirth is extremely limited.

There is potential for a parent of multiples to experience different but simultaneous reactions to the births of their children, particularly when the infants' antenatal courses have differed or one infant is less well than the other/s.

In instances of combined livebirth and stillbirth, celebration and profound grief coincide. At present, health care workers and family members have little evidence-based guidance to shape their responses, which (anecdotally) often fall short of meeting the parents' complex needs.

Accommodating maternal birth preferences in the context of singleton birth (such as skin-to-skin contact between mother and newborn in the operating theatre or recovery bay) is a relatively recent development. Consideration of these preferences in multiple births is also possible but there may need to be some modifications depending on circumstances. Development of flexible theatre and recovery, special care/neonatal intensive care and postnatal ward policies which identify and accommodate the needs of multiple birth families should be considered.

2.6 Areas in which maternal child health nurses would benefit from professional development/evidence-based information about multiple families

Janet Young

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Conducting a physical or developmental assessment on multiple birth babies and children poses no greater a challenge than a singleton check for the maternal child health nurse; after all, it is the essence of our training. Anatomical features should all be similar; multiples are more likely to face developmental challenges, but singleton babies present the same challenges; there is nothing unique in either group.

On a psychological level, the maternal and child health nurse and indeed any other professional who is consulting with the family may struggle. Having a multiple birth is a unique experience and may not be fully understood unless experienced first-hand. The emotional impacts of twins on the family are not always discussed. We can all ask questions relating to family violence, but may hesitate to ask about emotional health specific to multiple births. Not only do we not understand their full impact, it can be so varied.

Unfortunately, not all multiple pregnancies result in multiple babies coming home, and this in itself is a challenging area.

The surviving baby can be a constant reminder of the deceased baby; how do we broach the subject? I believe that few nurses feel confident that they do it well; they do the best they can but most have never had formal training.

Lack of sleep, age of parents, sharing attention and responding to multiple needs at the same time can all have an emotional impact on the family. Relationships can suffer because life becomes so busy; for example, babies are often released from hospital at different times, so babies are in different places.

Many parents describe the heartbreak they experience when they are discharged but their babies are not ready to come home. The pre-birth expectations of life with multiples are already shattered. As professionals, do we really know how to support parents in this situation?

2.7 Maternal child health nurse training: effective management and relationships with multiple and premature births

Ashlee Tenberge

Australian Multiple Birth Association (AMBA)

Every year in Australia, approximately 4,500 families experience a multiple birth. That's around 9,000 babies from a high-risk pregnancy. Multiple-birth families are a minority, have unique needs and face specific challenges. Multiple-birth families are five times more likely to experience pre-term birth and low birthweight, which occurs in 50% of all twin births and nearly all (95%) triplet and higher order multiple births (Martin et al., 2009). Multiple-birth families experience feeding and sleeping complexities, and higher incidences of delayed speech and physical disability. Carers have insufficient time to socially and emotionally engage with babies, and face challenges in participating in physical activity, including structured lessons and free play, due to physical and financial constraints.

Maternal child and family health nurses (MCAFHN) play a key role in the provision of community child and family health services and provide early contact with families.

Their early involvement with families and the impact of their relationship cannot be underestimated. MCAFHN have specialised knowledge of child development and know what's "normal". There is currently a gap in MCAFHN being able to offer consistent best practice advice, as there is no standardised training in relation to the differences between singletons and multiple births, which can create inequality and confusion in how MCAFHN engage with families.

Confusion during an already challenging life transition drives parents to seek opinions from multiple providers: general practitioners, paediatricians, midwives, child health nurses, pharmacy nurses, lactation consultants and emergency department staff. It's imperative that MCAFHN are appropriately trained to maintain a trusted, strong and well-informed relationship with multiple birth families so parents feel that their wants and needs are being heard and met and that they are active participants in the health journey. Trust is a critical factor influencing a variety of important therapeutic processes including patient adherence to recommendations, satisfaction with recommendations, and satisfaction with medical care (Cook et al., 2004).



One in five multiple birth mothers are diagnosed with post-partum depression (TAMBA, 2018), compared to one in seven families with a singleton. MCAFHN have a significant role to play in reducing isolation of multiple birth parents by connecting them to appropriate networks that will meet their extensive health needs. Effective management and relationships with multiples and premature babies comes from working in partnership with families and establishing strong communication and relationships with parents and carers.

A proactive, consistent and coordinated referral approach to specialised community services like the Australian Multiple Birth Association, sleep schools and enhanced MCAFHN services is urgently needed to ensure equity of care for multiple birth babies and their families. The lack of specialised training for MCAFHN in regards to the challenges and difficulties that multiple-birth families face calls for a review of antenatal educational programs to ensure the health system is working cohesively with families to achieve effective outcomes.

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2.8 Parenting in hospital

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Half of all twins, and more than 90% of triplets, need care in a neonatal intensive care unit and/or special care nursery. The logistical challenges for parents caring for more than one medically fragile child are considerable. These include:

- caring for children with differing levels of medical need (who may be in different sections of the nursery, or even different hospitals)
- juggling conflicting feed and care times
- few opportunities for physical contact with each child and with the children together
- the challenge (for many) of providing expressed breastmilk
- establishing oral feeding
- the practice of staggered discharge, in which one child leaves hospital before the other/s.

These challenges come at the same time as a mother must recover from a pregnancy which is likely to have been difficult, which may have included a period of physical deconditioning due to bed rest, and a birth which is more likely to have been surgical (by caesarean section) than not.

Breastfeeding initiation rates are lower among multiples, with prematurity the most consistent and significant impediment. Excellent lactation support is vital to assist mothers wishing to breastfeed. Guidelines have been established to help promote breastfeeding among families with multiples (Leonard, 2000).

Central to the guidelines is the principle that families of multiples should have access to sustained lactation support from skilled and informed health care providers. Mothers of multiples who are unable or choose not to breastfeed their infants also require support regarding the practicalities of formula feeding multiple infants.

Parents of multiples would benefit from greater guidance to navigate their unique circumstances while their children are in hospital, and advice on measures which may support family bonding and infant and maternal wellbeing.

For example, “Kangaroo care” is the practice of skin-to-skin contact between premature infant and parent, and has been shown to promote physiological stability of the infant, enhance emotional bonding and improve breastfeeding rates (Chan et al., 2017). Kangaroo care of twins requires planning and support. Each twin is assigned a breast. Maternal skin temperature has been shown to adjust independently on either side to accommodate the infants’ differing needs for warmth. Preliminary studies suggest that twins (and even triplets) may safely experience shared kangaroo care under close supervision, but more research is needed.

A large study involving single-born premature children found that parents reading to a child more than twice a week was associated with significantly improved cognitive outcomes at two years (even taking maternal education, socioeconomic status and neonatal complications into account). In the absence of twin-specific research, it would seem reasonable to recommend reading as an inexpensive and enjoyable intervention which may have longer-term benefits.

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2.9 Staggered discharge from hospital

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In addition to recovering from what is likely to have been a challenging pregnancy and birth, new mothers of multiples must tend to the needs of two or more infants who may be medically fragile. The contrast between the “cocoon” of care within hospital nurseries and the isolation often experienced by new parents of multiples following discharge from hospital can be striking. Closer liaison between nursery staff, families, maternal and child health care nurses and GPs is encouraged.

Specific to multiple birth circumstance is “staggered discharge”, in which one (or more) multiple birth infants is discharged from hospital days, weeks or even months before its co-multiple/s.

For a new mother of twins, this means that she will be providing care to a newborn (often prematurely born) infant who is at home, and travelling to and from hospital to visit and care for a co-multiple. If her hospitalised infant is receiving breastmilk, she will also be expressing and transporting her milk, while attempting to establish a feeding schedule with her discharged twin. Mothers in one study reported that staggered discharged increased the strain they felt, due to combining the demands of a prematurely-born newborn at home with the anxiety of a child still in hospital.

Research conducted during the 1970s and 1980s suggested that parents were likely to form a preference for the infant discharged from hospital first, and that such parental preference was maintained through to adolescence. These studies were, however, small in size and not representative of twins in general (involving female monozygotic (MZ) twins only). The validity of extrapolating from these studies to how parents of twins regard their children today is debatable.

In the past, parents of twins were often advised to take one twin home while leaving the other in hospital, to become accustomed to infant care. Today’s parents are highly unlikely to be offered the opportunity to take one twin home simply for “practice”, but intense pressure on resources, with fewer neonatal beds being available in nurseries than are needed, means a medically stable twin is nonetheless likely to be discharged before his or her less stable sibling. There is little data on parents’ experience of staggered discharge of multiples, and no studies at all of staggered discharge of male MZ or any dizygotic twins.

2.10 Adaptation to parenting multiples

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The physical workload of caring for infant twins or triplets is often underestimated. A breastfeeding mother of newborn twins is likely to be feeding them 16–24 times and changing 20 nappies each day. While number of feeds per day declines over time (from 19 at two weeks post-discharge from hospital to 13 at 20 weeks, in one study) at all ages, basic care needs are higher in multiples. In the neonatal period, while mother and babies learn to tandem (simultaneously) feed, feeds are often given separately, taking more time. Many mothers also mechanically express milk to increase or maintain supply (with 2¾ hours per day spent expressing, if recommended guidelines are followed). Another survey reported that it takes 197 hours per week to care for triplets, or 28 hours and 12 minutes per day; even if split evenly between parents, that’s nearly 99 hours per week each. Hay and colleagues (1990) reported that at three months, 43% of Australian mothers of twins were anxious, 30% depressed and 76% exhausted.

Mothers of infant twins have been shown to be significantly less likely to feel competent and confident looking after their children than mothers of singletons. Persistent infant crying has been associated with diminished maternal sense of competence. A mother of multiples has limited ability to respond immediately to two or more crying infants, so it is unsurprising that her sense of competence is undermined.

Education regarding patterns of normal infant crying (including the fact that non-response to soothing is characteristic) may help alleviate parental distress over a normal (albeit doubled) developmental behaviour.

At the extreme and tragic end of adult responses to intractable infant crying, multiples are believed to be over-represented among victims of non-accidental (inflicted) injury. The curve of infant crying over time is paralleled by the curve of incidence of “shaken baby syndrome” (Barr, Trent, & Cross, 2006), the consequences of which can be catastrophic. Education of prospective and current parents of multiples (mothers and fathers) must include explicit instruction to walk away if the infants’ crying becomes overwhelming.



Premature babies have been shown to give fewer cues to caregivers. Establishment of maternal identity and sense of competence in the context of premature multiple birth has not been investigated to date.

In the absence of specific evidence, health care providers are encouraged to explicitly acknowledge and praise parents (particularly mothers) for the parenting work they accomplish, encourage responsiveness to their infants’ cues, and advise them on the importance of minimising fatigue.

Some behavioural research into early parenting of twins has interpreted maternal efficiency measures (such as propping bottles or feeding twins from one dish) as indicative of disturbed maternal attachment to the infants. They may be more appropriately considered as inevitable by-products of the atypical mother-to-child ratio. Future research which frames maternal efficiency measures as adaptations to unusual circumstances, rather than as abnormalities, is needed. Developing an evidence base of time-saving measures and parenting strategies which liberate time for more important interactions or activities (such as supporting infant pre-language skills) would be more helpful than pathologising them.

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2.11 Parental mental health

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Parents of multiples are at considerably higher risk of mental ill health and early parenting difficulties than parents of single-born children. Rates of clinical anxiety among mothers of multiples are three times higher than among mothers of singletons; rates of depression are five times higher, and disabling exhaustion occurs nine times more frequently, contributing to 12 times the expected rate of admission of mothers and babies to early parenting residential services (“sleep schools” and mother–baby units).

Fathers of multiples experience twice the levels of anxiety, four times rates of depression and a five times greater prevalence of reduced daily functioning than fathers who have singletons.

Frontline health carers are encouraged not to view distress, fatigue or tearfulness as the inevitable consequences of parenting young multiples; they are better viewed as inevitable consequences of *inadequately supported* parenting. Raising awareness of the prevalence of mental ill health among this population, diminishing stigma and encouraging help-seeking and self-care, are worthwhile aims.

Improving parents' mental health strengthens their ability to respond to their infants' cues, promotes communication between parents and babies, and improves early childhood development in thinking, language and behaviour.

This is particularly important for multiples, as they are at significantly increased risk of developmental delays (Costello-Harris and Segal, 2018).

The challenges of the early years for parents of multiples are considerably better documented than the longer-term implications, but evidence suggests that while the demands on parents of multiples change over time, they do not recede. Increased rates of mental ill health and impaired parental quality of life persist at least to mid-childhood.

Research into parenting multiples has often focused on documenting increased prevalence of mental illness and parenting stress, rather than on the social structures which perpetuate these problems (such as isolation, chronic sleep deprivation, lack of respite and financial strain). Arguably, the time for documenting the burdens of parenting multiples has passed. A better use of limited research and intervention resources may be to identify and address modifiable risk and protective factors for mental illness.

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2.12 Co-bedding – a UK perspective

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Co-bedding multiples (putting babies together in the same cot) in the early days is highly popular both in hospital and at home because of its many perceived benefits. These include simulating the womb environment, promoting synchronised body temperatures and sleep cycles, soothing both babies, and reducing the amount of space needed for beds. However, there is a lack of conclusive evidence for the effectiveness of many of these measures, and further research is needed into the benefits of co-bedding.

Whilst we can use the existing safer sleep guidance to inform multiple-specific advice (for example, avoiding the risk of overheating by not sharing a Moses basket or baby box), other multiple-specific questions remain unanswered. Unfortunately, parents often find that they are unsure how to safely co-bed their multiples due to inaccurate or insufficient information and advice, either because it was not passed on to them by their health professionals, or because it simply does not exist. There is a lack of guidance about co-bedding triplets or higher-order multiples, and there is no information about co-bedding in neonatal care, despite a majority of UK multiples sharing a sleeping space in the hospital setting as well as at home.

Safer sleeping advice is imperative for multiples because they are more likely to be born prematurely and at a low birth weight, both of which are risk factors for sudden infant death syndrome.

Therefore, multiple-specific advice on how to co-bed safely in hospital and at home, including for higher-order multiples, along with clear evidence on the risks and benefits, is essential. It is also vital that relevant health professionals are aware of current guidance and confident in being able to pass this on to families so that they can make fully informed decisions about co-bedding.

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2.13 Co-bedding – an Australian perspective

Ashlee Tenberge

Australian Multiple Birth Association (AMBA)

Safe sleeping recommendations are imperative for multiples because they are, on average, five times more likely to be born prematurely (Martin et al., 2009) and at a low birth weight than singletons, both of which are risk factors for sudden unexpected deaths in infancy.

Co-bedding of twins was introduced in neonatal units around the 1990s. It's thought that co-bedding mimics co-regulation in utero, where twins interact with each other through touching or holding. Benefits of co-bedding can potentially promote growth and neurodevelopment, along with reducing apnea, improving bonding between infants, and saving cot space. However, current research into the co-bedding of twins does not provide sufficient evidence to either encourage or prohibit the practice in a neonatal intensive care unit (Jarvis and Burnett, 2009).

Existing resources and guidelines offer partial solutions to co-bedding of multiples, with incomplete and conflicting information resulting in parents not knowing how to safely co-bed their multiples.

We know that consistent modelling by staff of safer sleeping practices increases the likelihood of parents following safer sleeping practices once they are at home, but we also know that this modelling is often inconsistent in relation to multiples. There is also a significant lack of standardised guidance about co-bedding triplets or higher-order multiples.



Most of the existing safe sleep guidelines offer impractical advice when applied to infant multiples. Studies show that it is important to reduce the risk by placing a baby in their own safe sleeping place, but also that room sharing can reduce the risk of sudden unexpected deaths in infancy by up to 50% compared to babies sleeping in a separate bedroom (NSW Health, 2016). The realities of having two, three or more individual cots in the same room as a parent is impractical in most cases, calling for a review of guidelines and practical advice specifically addressing the needs and risk factors in relation to multiples.

Health professionals must be fully aware of current frameworks and guidelines and be confident in educating families so that they are equipped to make informed decisions about co-bedding.

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2.14 Feeding issues

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The World Health Organization recommends mothers should breastfeed exclusively for their child's first six months to achieve optimal growth, development and health. Thereafter, children should be given nutritious complementary foods and breastfeeding should continue up to the age of two years or beyond. For mothers of twins, triplets and other multiples, this can be a daunting statement. Many mothers simply cannot comprehend the idea of feeding more than one baby, particularly if they have fed a singleton baby previously.

In a joint NCT and TAMBA (2015) study, mothers reported that breastfeeding twins was stressful and time-consuming, and that additional support both antenatally and postnatally would have been helpful. Factors such as prematurity, smokers, lower education standards and maternal youthfulness (under 23) meant that twins were not exclusively breastfed up until the recommended six months. Women stated that a lack of preparation by their health professionals during the antenatal stage prevented them from trying or continuing to breastfeed. Being discharged too early and not receiving appropriate teaching from a midwife or a referral for breastfeeding support were other reasons. Commercialisation of formula and its benefits and messages that breastfeeding is unnatural (that breasts are sexual and not for feeding babies) also contributes to a low breastfeeding rate.

Women need to understand the value of breastfeeding and of their milk in general. They must be taught the importance of expressing at different stages; if babies are in neonatal intensive care, they can be syringe fed their mother's early milk to pass on nutrients. Health professionals will need to show mothers the techniques of hand massage and pumping to maximise the benefits.

Many parents lack knowledge of how to feed two babies and methods such as tandem feeding, mixed feeding and expressed milk.

Although technical advice for breastfeeding is available, health professionals need practice and confidence to pass this information on to mums successfully. With regards to weaning twins, many parents worry about the spreading of germs from one baby to the other. Research into whether it is safe to feed two or more babies with the same spoon would be helpful at this milestone for parents of multiples.

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2.15 The practical challenges of multiples

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Couples who plan on having a baby rarely plan on having twins or multiples, which are, however, a lot more common with increasing use of IVF and other artificial fertility-enhancement methods. The diagnosis of more than one baby in a pregnancy brings mixed emotions, from fear to excitement, and many unforeseen risks and consequences. The pregnancy can be uncomplicated or very complicated, maybe involving long antenatal stays in hospital due to bleeding, high blood pressure or premature rupture of membranes, just to name a few. More than one baby in utero increases the risk of prematurity and mortality, and the emotional impact of having to go to term (or as far as possible) with the other or others can be devastating. Less significantly but still importantly, increased size due to multiple pregnancy means more and larger stretch marks and altered body image.

After the birth the already sleep-deprived mother (who is typically unable to sleep during pregnancy because of discomfort due to uterine size) embarks on the challenge of juggling multiple babies, who are not governed by the same clock, 24 hours a day. Parents of multiples may have to exist on minutes of sleep rather than hours, catching snippets of sleep between feeds and needs. Dealing with the normal demands of life such as cooking, cleaning and washing can be done in a haze of confusion. A mother of twins once told me she was so tired that she filled her babies' bottles from the hot water tap by mistake. Having the two parents at home at this stage is helpful, as they can tag-team the routine; this is not great for the relationship, but at least four hands are better than two.



You might call having two parents present the honeymoon period for multiples, but of course they are more expensive than singletons and money doesn't grow on trees, so eventually one must return to work. Expecting a singleton baby but having more than one can be quite a financial surprise, which continues and grows as the children do. Expenditure on cots, car seats, nappies, clothing, food, childcare, dance lessons, music lessons, swimming lessons, school fees and extra-curricular activities, just to name a few, is two or more times higher.

Having a multiple birth can and should be a joyful occasion. Nonetheless, despite careful care and monitoring, multiple births mean complications, in every sense. Perhaps the answer is to relieve the financial burden to enable people to enjoy their children and to be the best parents possible.

Relief with childcare, school fees and the specific costs of multiples would be very welcome, and just not for health care card holders.

Chapter Three:

Socio-economic aspects and early education



3.1 Multiples, childcare, work and family finances

Helen Turier

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For many families, twins are not their first children. Analysis of the Millennium Cohort Study showed that 55% of twins were born to families that already had children, and in 24% of cases they had two or more children when their twins were born (McKay, 2010). Twins and multiples can have a significant impact on family finances, as they require additional one-off purchases and the ability to hand things down to the new siblings is diminished. It is not just the amount of new equipment that is needed that affects family finances but the time needed for the family to care for the new babies as well as older siblings. This, plus the increased workload of caring for two or more babies, can even result in the main wage earner having to reduce their working hours, thus resulting in loss of income.

In a survey conducted by TAMBA and the Australian Multiple Birth Association, one in every eight families reported having to reduce the working hours of the main wage earner because of the cost of childcare (TAMBA, 2013). The rate at which mothers return to paid work is also slower for mothers of multiple birth children than singleton babies. This could be because the cost of childcare will be higher with two or more same-aged children, making childcare costs unviable in some cases and a return to work impossible. However, there is a lack of evidence.

Further research is needed into the financial impact of multiple births on families.

This is needed in order to inform better policies about childcare provision and costs, as well as financial benefits for working families so that the needs of this vulnerable community are adequately met.

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3.2 The financial burden of very premature babies

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Very premature babies are those born before 30 weeks gestation. Whilst most multiples are born after 30 weeks, a significant proportion are born very prematurely. More than 50% of these premature infants will survive, but at what cost? It appears that no research has been conducted into the long-term costs to a family when their multiples are born very prematurely.

The costs for families begin as soon as the babies are born. If employed the mother will commence her family leave once she gives birth, so the family income is reduced – and with premature babies, sooner than planned.

The babies might remain in hospital for months, during which time the costs of travel to hospital, parking and incidentals such as lunch and snacks soon mount up.

Once the babies are home, ongoing health problems will prolong the increased expenses. Do they require regular medical appointments? Do they require regular therapy – speech, physio, etc.? While the health system may provide the treatment, there will inevitably be associated costs, such as transport. If the babies require ongoing treatment, it is unlikely that both parents will be able to work and family leave may be required for several years.

3.3 Higher rates of sick leave and hospitalisation of mothers of multiples

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Mothers of multiples are at particular risk of developing pregnancy-related complications. They are prone to complications that can affect singleton pregnancies (e.g. high blood pressure, pre-eclampsia, or diabetes) but also those specific to multiple pregnancies (e.g. twin-twin transfusion syndrome).

All complications require ongoing monitoring and in some cases, urgent treatment.

Mothers of twins report higher rates of sick leave during pregnancy. They are twice as likely as parents of singletons to have overnight hospital stays and experience more hospital admissions.

Common reasons for admission include managing complications, concerns about fetal movement, or growth, or preterm labour.

After birth, over 80% of singleton mothers in the UK are discharged within three days and only 18% stay four days or more (Redshaw, Henderson and Kurinczuk, no date). This compares to 61% and 67% respectively of mothers of twins and triplets who stayed four days or more. The differences are thought to be due to differences in method of delivery (caesarean section is much more common for multiples) and other complications from which mothers take longer to recover. There is also the far greater likelihood of twins and triplets being admitted to the neonatal intensive care unit. It appears that some hospitals allow mothers to stay for longer to support their own and their babies' health and wellbeing.

Research shows that in the UK, most partners report taking additional leave during pregnancy or shortly afterwards (McAslan Fraser, 2013). The most common reasons given were to help out after the babies are born (87%), to accompany the mother for pregnancy scans (59%), and to look after other children (27%) while in hospital and while pregnant (10%). Some employers, especially those who have had twins, tend to be very understanding and flexible for partners. Nonetheless, many partners reported difficulties in taking leave at this time.

References

McAslan Fraser, E. *Multiple births parents' experience of maternity and paternity leave*, 2013.
<https://www.tamba.org.uk/document.doc?id=516>

Redshaw M, Henderson J, Kurinczuk JJ. *Maternity care for women having a multiple birth* (no date). Oxford: National Perinatal Epidemiology Unit.
<https://www.npeu.ox.ac.uk/downloads/files/reports/Maternity-care-for-women-having-a-multiple-birth.pdf>

3.4 Childcare – education of twins

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Research shows the importance of play opportunities for all children in the early years, but parents of multiples find it difficult to access the activities available, due to reasons such as accessibility issues, financial strain and the logistics of handling two or more children alone. Research is needed to find ways to ensure that multiples have access to the same learning and play opportunities as singleton children.

In the UK, parents of twins and multiples feel that teachers, especially in the early years, do not have enough multiple-specific knowledge on how best to promote the learning and wellbeing of multiple birth children.

Policy-makers need to ensure that teachers receive multiple-specific training, either in initial teacher training or first-year continuing professional development.

Research shows that most multiples are kept together for at least the first year of school in the UK. We know that there are pros and cons of keeping multiples together. The UK government's position is that schools should not have a blanket policy on classroom placement of twins. Research shows that best practice is to listen to the parents and the children and respond case by case. The long-term effect on children when they are placed separately should be studied.

Recent UK legislation has made it possible for summer-born children (1 April – 31 August) to start primary school a year later than those born outside these dates. This is important for multiple birth children, who are likely to have been born prematurely. Researchers need to assess the effects on the children of delaying school entry, study the impact of prematurity on educational progress, and investigate the social and emotional development of multiple birth children.



Chapter Four: Recommendations



The numbers following each recommendation show its source/s within this document.

Recommendations for research

- Investigate therapeutic options that can prevent preterm birth in multiple pregnancies and reduce the risk of significant long-term adverse outcomes. (1.1)
- Evaluate the effectiveness of continuity of care by a multidisciplinary team. (1.2)
- Investigate the benefits of specialised twins' clinics. (1.2)
- Improve understanding of the best ways of supporting bereaved parents after loss of babies from a multiple birth. (1.5, 1.6)
- Examine the psychological effects on parents of an early loss of expected twins, or for the children who grow up in this context. (1.6)
- Determine the most effective ways to support families with multiples. (1.7)
- Clarify the pathways contributing to cerebral palsy in twins. (1.8)
- Develop standardised guidelines for antenatal care to ensure all expectant parents of multiples receive accurate, up-to-date, relevant information. (2.3)
- Undertake qualitative investigation of the experiences of women who have relatively uncomplicated multiple pregnancies, and of those with complicated multiple pregnancies. (2.4)
- Develop evidence about time-saving measures and parenting strategies which liberate time for more important interactions or activities. (2.9)
- Examine the effects of staggered discharge on multiple birth babies and parents. (2.10)
- Identify modifiable risk and protective factors for mental illness in multiple birth parents. (2.11)
- Study the benefits of co-bedding multiples. (2.12)
- Investigate the health effects of feeding two or more babies with the same spoon. (2.14)
- Examine the financial impact of multiple births on families. (3.1)
- Investigate the long-term costs to a family when multiples are born very prematurely. (3.2)

- Examine the potential benefits to mothers and babies of longer inpatient stays after multiple birth. (3.3)
- Find ways to ensure that multiples have access to the same learning and play opportunities as singleton children. (3.4)
- Assess the effects on the children of delaying school entry. (3.4)
- Study the impact of prematurity on educational progress. (3.4)
- Investigate the social and emotional development of multiple birth children. (3.4)

Recommendations for policy

- Ensure that NICE guidelines are embedded into current practice. (1.2)
- Provide universal, affordable zygosity recording and testing (if necessary) for all twins and higher order multiples, ideally at birth. (1.4).
- Develop structured, multiple-specific early parenting education programs. (2.2)
- Fund specific resources for parents of young multiples. (2.2)
- Develop flexible theatre and recovery, special care/neonatal intensive care and postnatal ward policies which identify and accommodate the needs of multiple birth families. (2.5)
- Develop a proactive, consistent and coordinated referral approach to specialised community services for multiple birth families. (2.7)
- Relieve the financial burden of childcare, school fees and the specific costs of multiples to enable people to be the best parents possible. (2.15)
- Permit mothers of premature twins and multiples to extend their maternity leave so it begins at their babies' due date rather than when they deliver. (3.3)
- Strengthen legislation permitting partners to take leave during pregnancy or after birth to support their families. (3.3)

Recommendations for education and training

- Provide better training for parents and clinicians to make them aware of zygosity and its many implications. (1.4)
- Health professionals who meet bereaved families of multiples must be trained to treat them with care and dignity. (1.5)
- Health professionals and professional bodies need to be more aware of the heightened support needs of families with multiples. (1.7)
- Ensure relevant health professionals are aware of current guidance about co-bedding and can pass this on to families so that they can make fully informed decisions. (2.12)
- Ensure that teachers receive multiple-specific training. (3.4)