



Acta Genet Med Gemellol 39: 507-514 (1990)
©1990 by The Mendel Institute, Rome

Sixth International Congress
on Twin Studies

An Agenda for Meeting the Special Needs of Multiple Birth Families

P.M. Malmstrom, R. Biale

Twin Services for Multiple Birth Families, Berkeley, California, USA

Abstract. Over 80,000 multiple birth babies are born each year in the U.S. Their families must cope with a constellation of complex physical and psychosocial challenges, which jeopardizes their health and functioning. The demands of twin pregnancy and the parenting of twins, triplets, quadruplets, quintuplets or more puts these families at disproportionately high risk for infant mortality, birth defects, child abuse, substance abuse, financial problems and marital problems. Health and social service resources must be developed to alleviate the stresses associated with multiple birth and to empower parents to cope well. Guidelines for policies, parent education, professional training and service delivery developed for the California Department of Health Service, Maternal and Child Health Branch, are here offered for the consideration of policy makers and public health planners.

Key words: Multiple births, Family problems, Social service

Notwithstanding the positive aspects of twinning and the very real joys multiples bring their families, the latter are subject to a constellation of stresses which jeopardize physical and mental health and family functioning. Apart from perinatal medical care and peer support offered in mothers of twins clubs, few resources exist in the U.S. to provide these families with the special health education, psychosocial support and care they need to cope well.

A total of 80,000 twins, triplets, quadruplets, or quintuplets are born annually in the U.S. The rise in postponed motherhood, recent advances in infertility treatment, in vitro fertilization, and neonatology, are contributing to an increase in the numbers of

Special Project of the California Department of Health Services, Maternal and Child Health Branch, Contract No. 87-91072.

multiple-birth babies who are born and survive. According to the National Center for Health Statistics, multiple birth infants (hereafter collectively called twins) rose a total of 3% in 1985 and 1986 alone [12]. Altogether, there are some 660,000 multiple birth children under the age of ten in the U.S. and approximately 330,000 family constellations of parents, siblings and other relatives involved in the challenges of their care. One out of every 45 Americans is a twin or triplet and one out of every 20 Americans is directly impacted by a multiple birth.

In California, where 9,600 multiple birth infants are born each year [16], the Department of Health Services has funded the development of a health education and social service agency called Twin Services (formerly known as TWINLINE) to provide health education and psychosocial services for multiple birth families. Since 1978, Twin Services has assisted thousands of families nationwide through a variety of services. Services for parents, parents clubs and service providers include a professionally staffed telephone (the "Twinline") for counseling and referral; a variety of free and low cost publications about twin care and development; and, in the San Francisco Bay Area, classes, seminars, clothing and equipment exchange, and a respite care program for low-income multiple birth families in crisis.

COMMON CONCERNS OF TWIN SERVICES' CLIENTS

Twin Services' records dramatically illustrate the needs of multiple birth families. The issues raised most often by parents and expectant parents of twins are:

- Medical management of plural pregnancy and delivery, eg, tocolytic drugs, bedrest and cesarean section;
- Practical management of the care of multiples, eg, equipment, supplies, housing, transportation;
- Twin rearing, eg, zygosity testing, breastfeeding, care of newborns and premature infants, sleeping and eating habits, toilet training, biting, school placement, language development, twin bonding and competition between the twins and with other siblings;
- Stress management;
- Disability or death of a twin.

These problems, in varying degrees and combinations, affect multiple birth families at virtually all socioeconomic levels. Economically advantaged two-parent families report high stress from illness, financial difficulties, baby care and marital problems.

GENERAL SITUATION OF MULTIPLE BIRTH FAMILIES IN THE U.S.

The economic and social environment in the U.S. in the 1980s is not well structured to support the needs of twin families. Nuclear families are frequently separated from the relatives who might in earlier times have been able to give emotional support and help with child care. This means many families must cope in isolation without adequate sleep

for weeks at a time. They suffer from the extreme fatigue imposed by the care of two or more infants simultaneously, and often, the difficulties of caring for premature and medically fragile babies. Financial hardship increases quickly when there are extra medical costs, as there frequently are in the care of premature multiple birth infants. Families dependent on two incomes may flounder economically for years when the mother's health and/or the high cost of childcare for multiple babies prevents her return to work. There are additional expenses for double supplies and equipment, and, often, the cost of moving to larger quarters, although the high cost of housing frequently means that a family must struggle to live in an apartment too small to accommodate its needs.

As a consequence, families bearing multiples are at significant risk for psychosocial problems including a child abuse rate 2.5 times higher than that of the general population, increased incidence of parental alcohol and/or drug abuse, and marital dysfunction and divorce [11,13].

These difficulties are compounded in a variety of special circumstances. Single parents without the help of other adults often find it impossible to maintain the household and continue working. Low income families, homeless families and refugees who are already struggling to escape the downward spiral of poverty are easily overwhelmed by the arrival of twins. Teen mothers, a population at high risk for preterm labor to begin with, suffer an increase in premature delivery and neonatal loss with twin pregnancies.

The Afro-American population, which is overrepresented in these circumstances [9], has the highest twinning rate and is therefore at highest risk for this double jeopardy.

INADEQUATE RECOGNITION AND RESOURCES

With the exception of the "high-risk pregnancy" designation, multiple birth families have no official recognition as a population in need of special services. Social service and public health departments, hard-pressed to serve the enormous population of needy parents, have little time and few resources to provide the extra attention and education multiple birth families so desperately need.

Furthermore, there is a general lack of basic information about twin pregnancy and twin development. Prevailing mythology and folklore can mislead parents and providers with unfortunate consequences. For example, the stereotypical view of twins as smiling, healthy look-alikes, perpetuated in television commercials, falsely prepares expectant parents for the tremendous challenges of twin care. Unwitting parents, who fail to develop support networks ahead of the birth of their twins, find themselves overwhelmed.

Among common misconceptions about twin dynamics is the idea that there is always a dominant twin and a passive twin in each pair, or that one is "good" and the other is "bad". Without accurate information about the shifting balances of the twin relationship, parents or providers may assign such roles to twin infants, and the children will suffer the psychological damage of negative labeling.

The current crisis in the delivery of prenatal care has a devastating impact on infants. Studies show that nonmedical services, such as parent education, psychosocial assessment, counseling and nutritional guidance, are not only vital in and of themselves, but also promote access to an utilization of prenatal medical care. Comprehensive prenatal care becomes critical in the case of plural pregnancies. Multiple gestation carries in-

creased inherent risks, such as premature delivery (approximately 35% of twin births and nearly 100% of higher order multiples), the use of tocolytic drugs, low birthweight (60% of twins are born weighing less than 2500 g, and 10% are “very low birthweight”, ie, weigh less than 1500 g), and a perinatal mortality rate five times higher than that of singletons [3,8,14,15].

Nurses and social workers report that information and services for their multiple birth patients are shockingly inadequate. To the authors’ knowledge, no comprehensive curriculum is available which teaches appropriate assessment, management and referral techniques for the special needs of this population, although nurses and social workers are in an optimal position to provide such services and are often called upon to do so. This situation hampers providers in their efforts to provide high quality care, especially during three critical phases – pregnancy, delivery and the postnatal period. Furthermore, the general community and even Mothers of Twins Clubs have had little awareness of, or outreach to, low-income multiple birth families where needs are often highest.

American Mothers of Twins Clubs provide social support, survival strategies, and sometimes clothing and equipment exchanges for their 9,000 members. Valuable as these services are, however, the clubs are not a panacea. Their voluntary nature limits the scope of their outreach, information and services. These mothers of twins have limited time and, for lack of professional training, are often unable to offer appropriate help to families that turn to them. For example, some clubs exclude *expectant* parents from membership precisely because club members know they are unprepared to counsel a family that suffers prenatal or neonatal twin death.

Although current books and magazines on twin parenting offer a great deal of valuable information, they are not generally available in bookstores nor are they within the financial reach of all twin families. Since it appears that more than one out of five Americans is illiterate (and this trend is on the rise), literature on twin parenting is indeed a limited resource of information and help. Moreover, written materials, even when accessible and useful, still do not provide parents with the physical help, validation, and personal encouragement which they so badly need.

SPECIFIC NEEDS OF MULTIPLE BIRTH FAMILIES

Education, training, and social services for multiple birth parents have a tremendously beneficial impact on the health and development of infant twins, triplets, and more. For maximal benefits, these services must begin in the prenatal period. In order to assure prompt prenatal services to expectant parents of multiples, educational services must begin before conception to alert both the general public and the professional community to the risk factors for conceiving multiples. Early diagnosis of a plural pregnancy is vital for insuring good medical prenatal services.

In addition to appropriate medical management of the plural pregnancy, essential nonmedical services should be provided, including psychosocial assessment and counseling, training in breast- and bottle-feeding, education, nutritional counseling, and advocacy. Resource referral should assure access to appropriate basic resources, including housing, welfare and WIC programs, baby supplies and equipment, and community

resources for child care assistance. These services are critical components in the care of twin gestation, and are necessary to assure an optimal pregnancy by preventing preterm delivery and supporting the family structure in time of extraordinary stress.

The birth of same sex multiples presents the need to know the infant's zygosity. For important health and psychological reasons, parents and providers need to know whether or not their multiples are identical (MZ) or fraternal (DZ). MZ twins share the same risk for heritable diseases and SIDS. Discrepancies in their developmental patterns signal problems to investigate.

Feeding two or more infants is a formidable challenge, even when no other complications exist. Hospital personnel must be able to coach parents in techniques for bottle- and/or breast-feeding of two or more infants together.

At home, sleep deprivation, economic hardship, lack of in-home help and lack of time for parents to be alone are the major sources of stress reported by parents during the first year [1-3,5,13].

As the babies grow, the family undergoes new stresses. During the toddler stage, the demands of care are intensified by sleep disruption, increasing mobility of the children, and their struggles for independence. Difficulties with language acquisition and socialization may arise at this stage and increase parents' challenges [6,7,10].

At school age, twins and their families grapple further with issues of independence, social expectations and school systems which all too often deny families the choice of appropriate class placement for their children [6,7,10].

In order to cope, families need support networks of relatives, friends, neighbors, other parents of twins and (where economically feasible) hired caregivers. Ideally these networks would meet all the family's needs for help with baby care housework, shopping, acquiring necessary equipment and clothing, and would supply emotional support, as well as accurate information about twin development [4,11].

CONCLUSION

The unique stresses of multiple birth families deserve special attention from the medical and social service world. Multiple birth families who have appropriate information, counseling, and help can make positive adjustments to this life-changing experience. When their needs go unmet, multiple birth families can easily become trapped in insurmountable difficulties which put them at higher risk for neonatal death, disability, premature birth, child abuse, divorce, physical illness, alcoholism, sibling maladjustments and economic disaster. When this happens, the adults and children must increasingly depend upon government programs for support at escalating psychological and financial costs. Research and the allocation of resources are urgently needed to meet their special needs.

The following recommendations address these issues by proposing policies, education, service delivery, and research, to improve the health and welfare of multiple birth children and their families from the prenatal period through adolescence [17]. Drawn up specifically for California's Department of Health Services, these recommendations reflect the needs of the multiple birth population nationwide.

Recommendations

1. *Supportive Policies*

- a. That the condition of a multiple gestation and birth automatically classify a family as at “ high psychosocial risk ”.
- b. That care plans for parents and expectant parents of multiples include special education and service according to their needs.
- c. That maternity- and paternity-leave policies provide extended leave for parents expecting or caring for newborn multiples.
- d. That birth and fetal death certificates include multiple birth data, including zygosity, type of multiple birth and status of cotwin(s).
- e. That laboratory testing for zygosity be underwritten by insurance companies and that testing be standard procedure at the births of all multiples when zygosity is in doubt.
- f. That insurance companies underwrite the cost of home care for: expectant mothers of multiples on medically ordered bedrest; families with newborn multiples; families with premature or disabled infant multiples; families with triplets, quadruplets or quintuplets.
- g. That physicians and dentists be encouraged to give discounts for treatment of multiple birth children.
- h. That families with multiple birth preschool children be given the highest priority rating for subsidized childcare programs.
- i. That California school district policies on the classroom placement of multiple birth children accommodate the individual psychosocial needs of each set of multiples.

2. *Education*

- a. That families expecting multiple birth children and parents of multiple birth children have access to specialized parenting education and to psychological/emotional support throughout the child-rearing years, to enable them to cope well and make informed choices in the guidance of their multiples.
- b. That all obstetrical and pediatric medical personnel, social workers, school administrators and teachers be educated about the psychosocial needs of multiple birth families through the established mechanisms of continuing education and licensing requirements.
- c. That public education about the needs and care of multiple birth children be given through the media.

3. *Service Delivery*

- a. That a California Multiple Birth Registry be established to record vital statistics regarding multiple birth children.
- b. That a voluntary data bank on California multiple birth families be established for parents and service providers.
- c. That a California Multiple Birth Respite Fund be established to provide funding for multiple birth families in need of emergency care.
- d. That interdisciplinary “ Twin Teams ” be developed for each of California’s 14 Health Service Areas to:
 - provide specialized education, counseling and advocacy for multiple birth parents and health service providers in the service area;
 - advise in the development of care plans for multiple birth families;
 - connect multiple birth families to appropriate community resources;
 - administer emergency respite as described in n. 3 above.

The idea of the “Twin Teams” is to recruit a group of professional health and family service providers (such as obstetricians/gynecologists, pediatricians, RNs, public health nurses and social workers who are familiar with the needs of multiple birth families) to whom all parents of multiples and/or their primary caregivers could have access. The composition and location of the teams, might vary from area to area, but the purpose would be the same. For example, large urban areas might have a “Twin Team” in each major hospital. In rural areas, a team could be composed of one member of each perinatal clinic’s staff with a public health or visiting nurse to coordinate.

- e. That volunteer parents from the Parents of Twins Clubs in California be trained to give peer counseling to expectant parents and parents of multiples in their communities and to make appropriate referrals to community resources.
- f. That Twin Services be a resource for the above service delivery systems by generating research, education materials and training models for the twin teams, public health community and parent volunteers, and coordinating the California Multiple Birth Data Bank.

4. Research

That research about multiple birth families be given top priority in the following areas: symptoms of twin pregnancy; management of twin pregnancy; nutrition in twin pregnancy; stages in twin development of individuation; language acquisition; school policy and the classroom placement of multiple birth children.

REFERENCES

1. Anderson A, Anderson B, McInnes S, Malmstrom P (1985): The impact of multiple birth upon families. Paper given at Parents of Multiple Births Association Canada Convention, Edmonton, Alberta, May 5.
2. Bryan E (1986): Support for parents who lose a newborn twin (abstract). *Acta Genet Med Gemellol* 35(3-4).
3. Buckler J (1986): The social consequences of having higher multiple births in the family (abstract). *Acta Genet Med Gemellol* 35 (3-4).
4. Glaser K (1987): A comparative study of social support for new mothers of twins. In Boukydis CFZ (ed): *Research On Support for Parents and Infants in the Postnatal Period*. Norwood, NJ: Ablex Publishing Corporation.
5. Goshen-Gottstein E (1980): The mothering of twins, triplets and quadruplets. *Psychiatry* 43:189-203.
6. Hay D, O’Brien P (1987): Early influences on the school social adjustment of twins. *Acta Genet Med Gemellol* 36:239-248.
7. Hay D, O’Brien P, Johnson C, Prior M (1984): The high incidence of reading disability in twin boys and its implications for genetic analyses. *Acta Genet Med Gemellol* 33:223-236.
8. Hobel C (1988): *Twin pregnancy: “Sharing”*: Prenatal – intrapartum – newborn: Information and guidelines for care. Draft #9. Los Angeles: California Department of Health Services.
9. Lazarus W, West K (1987): *Back to basics: Improving the health of California’s next generation*. Los Angeles: Southern California Child-Health Network.
10. Malmstrom P, Faherty T, Wagner P (1988): Essential non-medical perinatal services for multiple birth families. *Acta Genet Med Gemellol* 37:193-198.

11. McInnes S (1979): The impact of a multiple birth on the family in home help and social services. Lethbridge, Alberta, Canada: Parents of Multiple Births Association of Canada.
12. National Center for Health Statistics, Hyattsville, MD (1988): Monthly Vital Statistics Report, 37 (July suppl.).
13. Nelson H, Martin C (1985): Increased child abuse in twins. Lexington, KY: Report of Department of Psychiatry, University of Kentucky Medical Center.
14. Papiernik e, Mussy M, Vial M, Richard A (1985): A low rate of perinatal deaths for twin births. *Acta Genet Med Gemellol* 34:201-206.
15. Persson P, Grenner L (1989): Towards a normalization of the outcome of twin pregnancy. *Acta Genet Med Gemellol* 28:341-346.
16. Rust KJ, Rust FP, Williams RL (1986): 1979-1983 Maternal and child health data base descriptive narrative. Santa Barbara, CA: Health Data Research Facility Community and Organization Research Institute, University of California-Santa Barbara.
17. Twin Services (1987): Twinshock: Issues in the care of multiple birth children. Berkeley, CA: Twin Services, Special Project of the California Department of Health Services, Maternal and Child Health Branch.

Correspondence: P.M. Malmstrom, M.A., Twin Services for Multiple Birth Families, P.O. Box 10066, Berkeley CA 94709, USA.