Research needed

Over the years here at CLIMB, it’s been obvious how much research is needed on almost every aspect of loss in multiple birth. But if there is one area in which research is most painfully lacking, it is that of the death of both of all the babies, or what some call complete multiple birth loss. Around 35% of CLIMB’s membership is, and has always been, parents who have experienced the deaths of their two, three or more babies, with no survivors, and almost not a day goes by without hearing from someone with this tragedy – yet to the best of our knowledge, no ongoing statistics exist that show what percentage of the time this is the outcome of a multiple pregnancy and birth.

However, a study by Hartley, Emanuel, and Hitti (2001) that utilized birth and death certificates for Washington State over 11 years, showed that of the 1 in 20 families who experienced death in twin pregnancy from 20 weeks’ gestation to 28 days after birth, a full 45% experienced the death of both twins; even of those who did have a loss after 36 weeks, 10% experienced the death of both of the babies. The one set of matched data produced by the Centers for Disease Control, for 1995-2000, for twin loss from 20 weeks' gestation to birth, showed that of the 1 in 16 mothers lost one or both babies in that timeframe, 47% of them lost both (CDC, 1995-2000 Matched Multiple Birth Data Set, CD-ROM Series 21, No. 17). (Because this was based on fetal deaths and live births, and many twins are born very prematurely and both die within hours or days of birth, this method undercounted the numbers of twins who do both die, though not necessarily their proportion of twin loss compared to the death of one of the babies.)

This is important in several ways: 1) to know how many actual families each year are affected by loss in multiple birth (when looking at the total number of babies who have died)(as discussed in the previous article);

2) for those attempting to conceive with the help of fertility technology to know–if they conceive multiples, and if they do experience a loss–whether they are more likely to still bring home a baby, or more likely to bring home no one at all, something that would be important in their decision making about how to proceed;

3) to show that the death of two babies from one pregnancy and birth is not an extremely rare event that does not merit much attention, but rather one that is impacting thousands of families annually in ongoing ways that deserves recognition and appropriate support, as well as medical research and prevention.

Medical topics which have not received much attention include the most prevalent timing of the loss of both or all the babies, the causes of it in addition to prematurity and/or Twin Transfusion Syndrome, and whether these have any implications for standard prenatal care. Loss of both babies in the third trimester tragically occurs on a regular basis and as yet has received little or no specific research attention. There is much literature on "the vanishing twin", the loss of a multiple in-utero in the first trimester or first 20 weeks of pregnancy, but none that we have been
able to identify on the rate or causes of loss of both twins or all higher multiples during those
timeframes, even though there is generally early diagnosis of multiples and this may be one of
the biggest contributors to the true extent of loss in multiple birth.

Most of all, from the point of view of CLIMB's mission, nothing at all besides CLIMB's efforts
has been done to acknowledge or study the grief features and needs of the parents and families
who experience the deaths of two, three, or more babies from the same pregnancy and birth,
sometimes all at once, sometimes over a period of days, weeks or months, often as their first
experience of parenthood: what are the most effective interventions at the time, and what are the
most effective forms of support over what period of time, taking into account also that most
parents also face the imperative to try again for another pregnancy as soon as possible, some of
them with the help of fertility technology. CLIMB and other groups offer potential access to
parents who have experienced this kind of loss and grief and we encourage qualified people in
search of important but unexplored topics to consider this one.

Jean Kollantai

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