

Collateral Damage: Is the Picture We Present Complete Without Discussing it?

Rob Graham, R.R.T./N.R.C.P.

I dedicate this column to the late Dr. Andrew (Andy) Shennan, the founder of the perinatal program at Women's College Hospital (now at Sunnybrook Health Sciences Centre). To my teacher, my mentor and the man I owe my career as it is to, thank you. You have earned your place where there are no hospitals and no NICUs, where all the babies do is laugh and giggle and sleep.

Every consult before a baby's anticipated preterm birth includes a discussion about outcomes, as do subsequent discussions when serious sequelae resulting from their prematurity are expected. The only tools we have at our disposal are statistical outcomes at each post menstrual age (PMA). These statistics, at least emotionally, may mean little to parents for which the only meaningful statistics are "0" and "100" percent; their baby is either going to survive or not, and with or without morbidities (0 or 100) and most cling to the belief that their baby will win the outcomes lottery, statistics notwithstanding.

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Regardless of what information we convey to parents, it invariably focusses on the baby. Since our focus is on the immediate care and treatment of babies this is understandable, but there are factors that influence the outcome of a child, for better or worse, unrelated to their relatively brief stay in the NICU. Those outcomes also impact others in the household.

Many studies have been done examining the quality of life (QOL) of former preterm infants relative to those born at term. From their perspective (self-reporting) the majority of former prems are happy with their lives, although there are several influencing factors. An in-depth analysis of 18 studies found no conclusive evidence to suggest any differences between those born at term or preterm. The studies' participants ranged in age from 18 to 36 years with a birthweight of less than 1500 grams, and while no significant differences were revealed, those with physical disabilities tended to score lower on QOL surveys. (Along with males in general, they were also more likely to decline participation.) The influence of preterm birth on QOL tends to be greatest early and diminish with age, although the study acknowledged that the demands of life later in adulthood could lead to a return in perceived QOL from either a physical or mental health aspect (1). It is noted that

recent findings show that extremely premature infants as adults are "lagged behind their term-born peers in related areas of long-term psychosocial outcome, such as wealth and engagement in romantic partnership and sexual intercourse" (1).

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While the U.S. Declaration of Independence states "...all men are created equal...", this does not play out in the real world. Socioeconomic status (SES) is a major influencing factor on many aspects of life, not the least of which is health. The mechanisms by which SES effects health are multifactorial, but lower SES is associated with shorter life expectancy and overall health (2). This has major implications for those who survive premature delivery with significant physical or mental morbidities. The relationship between SES and preterm birth are not clear, but the rate of preterm birth increases with declining SES via various mechanisms (3). One study found no direct difference in preterm birth and SES, but found food insecurity, stress, and inadequate prenatal care significant risk factors (4). Since these factors are most prevalent in lower SES populations, it is hard to explain why this is not reflected in the study's findings.

"The influence of SES does not end at delivery. Neuroplasticity is a big buzzword in medical rehabilitation circles. With the preterm infant, neuroplasticity is both good and bad. Aside from prematurity, many aspects of the care given and the environment of the NICU adversely affect the developing brain (5)."

The influence of SES does not end at delivery. Neuroplasticity is a big buzzword in medical rehabilitation circles. With the preterm infant, neuroplasticity is both good and bad. Aside from prematurity, many aspects of the care given and the environment of the NICU adversely affect the developing brain (5). Mitigation of the effects of brain injury requires timely identification and intervention. Therapy such as constraint-induced movement therapy to

facilitate the habilitation of babies with cerebral palsy shows great promise but is most effective when commenced early while the brain is still developing and most receptive to intervention (6). This is where things get messy.

“Children of parents with lower SES are much less likely to receive treatment for their morbidities for several reasons. They are more likely to be lost to follow-up where problems are identified and corrective treatment plans are made, and these children have more significant neurological impairment than those not lost to follow-up. Among other factors, children of multiparous mothers are least likely to attend follow-up (7).”

Children of parents with lower SES are much less likely to receive treatment for their morbidities for several reasons. They are more likely to be lost to follow-up where problems are identified and corrective treatment plans are made, and these children have more significant neurological impairment than those not lost to follow-up. Among other factors, children of multiparous mothers are least likely to attend follow-up (7). These families are far less likely to have a breadwinner with healthcare benefits to cover the cost of therapeutic interventions and other expenses necessary for the care of a high-needs child.

“It stands to reason that having other children at home places much greater demands on a mother and the time afforded to provide the care and attention a high-needs child requires. The day of a parent with a high-needs child does not have more minutes than any other day, and more time spent with one child dictates less time spent with another.”

That multiparous parents are less likely to bring their children to follow-up clinics for on-going care and assessment brings us to the discussion of collateral damage. It stands to reason that having other children at home places much greater demands on a mother and the time afforded to provide the care and attention a high-needs child requires. The day of a parent with a high-needs child does not have more minutes than any other day, and more time spent with one child dictates less time spent with another. This impacts the childhood and development of “normal” children in the household. A 2013 study of children with high-needs siblings “were more likely to have problems with interpersonal relationships, psychopathological functioning and functioning at school than siblings of non-disabled children” (8). This does not

have to be the case. Siblings of autistic children may show beneficial attributes (9), but these decrease as a sibling’s responsibilities increase and their inclusion in decision-making decreases (10). Parents of low SES are less likely to have outside help, are more likely to have to work, and have little choice but to off-load caregiving responsibility to their other children. It takes a concerted effort to keep this from happening, some of which can be found here (11).

“A large study out of China reports a protective (but varying) effect of children on a marital relationship, which is reflective of Western studies on the subject (12). Statistics from the Organisation for Economic Cooperation and Development (OECD) do not bear this out. OECD data indicate that having children increases the chance of marital breakup; of reporting OECD countries, an average of 44.4% of marriages without children end in divorce cf 54.6% of those with children (13).”

It is well known that children place a strain on relationships (an old joke about having children being the best form of birth control comes to mind!). A large study out of China reports a protective (but varying) effect of children on a marital relationship, which is reflective of Western studies on the subject (12). Statistics from the Organisation for Economic Cooperation and Development (OECD) do not bear this out. OECD data indicate that having children increases the chance of marital breakup; of reporting OECD countries, an average of 44.4% of marriages without children end in divorce cf 54.6% of those with children (13).

Marital stress is multiplied when a high-needs child is involved. In the U.S., approximately 20% of those married in the 1990s were divorced within 7-8 years (14), and it is widely reported that approximately 50% of marriages end in divorce. When a disabled child is added to the mix, that number jumps to 87%. Parents of autistic (ASD) children have a divorce rate of approximately 80% (15). A large Swedish study showed that extremely premature infants (23-27 weeks PMA) were three times as likely to have ASD as those born at 37-42 weeks PMA (16). The number of children with ASD will increase without a doubt as preterm birth and earlier PMA infants survive.

A large French study found that gestational age had no direct bearing on marital breakup; however, “non-optimal” neurodevelopment increased the risk of breakup, aggravated by low SES. Given the increased risk of abnormal neurological development in the extremely preterm, it stands to reason that this increases risk by extension. In all, 10% of relationships had ended within seven years (median 22 months) (17). Several exclusions in this study might be responsible for the relatively low separation rate reported.

When the family unit breaks apart, children of those with lower SES suffer the most. Children born into affluent families are more

likely to continue to receive support after marital breakup because the amount of child support their custodial parent receives is greater, and they are more likely to be included in at least one parent's benefits. Contrast this with those of poor SES. Mothers almost invariably end up with custody of children after divorce, and since they usually earn less than the non-habiting parent, they are placed in a precarious position. Child support is lower (if collected), and childcare needs can be insurmountable when seeking employment. Even less time can be spent with her high-needs child at a time when maternal attention is most crucial to neurodevelopment. Siblings invariably will be called on to take up the slack, impacting their emotional and social development.

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The final insult to a special needs child occurs as they enter adulthood. While it is sometimes possible to keep a disabled adult child under parental benefits beyond the age of 26, this is far from guaranteed and requires the supporting parent to have benefits that cover them at the time (18). Employers may well balk at the prospect of having a disabled adult adding to the cost of their health-care coverage, and if no benefits are in place at age 26, there will be no coverage other than that provided by government programs. In Canada, the parents of a child under age 18 who meet the criteria for disability may receive a maximum of \$264.41/month (Canadian \$). Ontario adds a maximum of \$1308 for a maximum of to this and provides basic dental and drug coverage as well as support for assistive devices. The monthly total of \$1572.41 is \$531.92/month, lower than the Canadian poverty line for a single person. If able to work, a disabled person receiving support may earn up to \$1000/month before benefits are reduced. The average cost of a bachelor apartment in Toronto is \$1317/month.

“The abysmal support for the disabled and the living conditions forced upon them by it has driven some to seek medically assisted death (legal in Canada). Understandably, this has ignited an ethical firestorm; however, there is no political will to improve the plight of those caught in the trap that poverty is, regardless of cause.”

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Beyond discharge outcomes, many factors may negatively influence a child's long-term outcomes. The sad fact is that many families do not have the tools nor the resources to change them, and they may not know this when making the agonizing decision to accept or decline resuscitation of their extremely premature baby. Without this knowledge, are they able to make a truly informed decision?

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