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CLINICAL SPOTLIGHT

Preterm birth: Understanding a mother's experience

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The World Health Organization (WHO) defines live births before completing 37 weeks of pregnancy as preterm. According to WHO, up to 18% of births worldwide annually are preterm birth.[1] In the Kingdom of Bahrain, preterm birth rate accounted for 10.26% in 2012.[2]

Giving birth to a child can be an event which brings joy as well as stress with it. But when a mother gives birth preterm and is told the infant may not survive or may live with severe disabilities it can be a whole different and unexpected journey for her. According to Jotzo and Poets,[3] a preterm birth can cause traumatizing symptoms that may last up to 18 months from the infant's discharge date. These symptoms include post traumatic stress disorder (PTSD),[4] guilt,[5] anxiety, and depression.[6]

In response to a self-designed questionnaire,* a mother of twins born at just 24 weeks, whose surviving twin is now 2 years of age, stated:

I suffered from great emotional distress. One of the main reasons for this was I felt I had no one to turn to. No one who could reassure me or provide me with comfort when my little twin girl passed away. Distress at the fact that all of this was happening when it shouldn't be, and I didn't understand why and what was happening. I believe I am suffering from long term emotional distress as I still cannot to this day enter a maternity ward for any reason. I often find myself going back to the events that happened that day and wondering if I could have done anything and did I do everything I could?

Another mother of a singleton born at 29 weeks stated:

As soon as my water-broke at just 29 weeks, I was thrown into what seemed like a never ending whirlpool. The emotional distress was unbearable, but I had to be strong for my baby and for my family. As it was my first pregnancy I had never considered delivering prematurely and therefore knew nothing at all about prematurity. It was horrifying! Seeing a baby so small and so delicate in a glass box for the first time was so shocking that I can still live that exact moment over and over again. Yes, that tiny being was my baby girl, in an incubator, and yes this image will forever be engraved in my memory. We knew nothing about the special machinery and tools that were to be used on our miracle baby, but today we are experts. The terminology used by the doctors made nothing easy on us, everyday we heard something new, new terminologies, new abbreviations which made things even more difficult. It was not until my baby reached 40 weeks that I could start to see my baby as a normal baby. 11 weeks of unbearable distress and discomfort was nothing less than the most scariest roller-coaster ride, ever built.

Although some of these symptoms may be situational and resolve once the infant's health improves, other symptoms may lead to serious or long-term problems. These may include the following:

- **RISK OF UNRESOLVED TRAUMA**: A research study investigated the effect of

psychological intervention on mothers of premature infants in the Neonatal Intensive Care Unit (NICU). It found that 59% of the mothers in the control group (i.e., without intervention) suffered from trauma symptoms at discharge time.[3] Moreover, unresolved trauma may lead to PTSD, which causes long-term psychological distress and could become chronic. This can affect the parents' well-being.[4] It can also affect the infant's sleep and eating behavior.[3] This problem can be seen as a threat in Bahrain where there is a shortage of specialized trauma therapists.

- **RISK TO PARENT-INFANT RELATIONSHIP**: The infant's environment and parent-infant relationship can be affected by parents' low self-confidence due to poor psychological well-being.[3] Bahraini society norms place high expectations on mothers to become the sole responsible caregiver in the family, despite her psychological needs. This may affect her well-being and self-confidence further.

- **RISK TO MOTHER-INFANT BOND**: In some cases, a delay may be noticed in the mother-infant bond until the infant is more physically stable and the risk of survival is higher.[7] The author can comment on this from personal experience as she was unable to relate to her premature twins as infants for weeks due to lack of "infantile behavior,"[7] as well as impeding wires and breathing aids attached to the infants.

- **RISK OF ABUSE AND NEGLECT**: In other extreme cases, the premature infant may be neglected or even abused due to mental or physical disability. There is a possibility of finding this in some Bahraini families where such disabilities may be stigmatized.

- **TRAUMA ACCEPTED AS DESTINY**: In the Bahraini society, trauma is seen as a person's destiny which he or she has to willingly accept and may be seen as ungrateful if complained about. During the author's infant's 97-day stay in the Salmaniya Medical Complex NICU, she was fortunate enough to informally provide counseling to some mothers who sought her help. In spite of their distress and case's severity, these mothers neglected their feelings believing that it was their "written destiny." While this may help some to resolve their trauma, it may also cause risk of repressing symptoms of depression, anxiety, grief, guilt, or anger. These repressed emotions can lead to serious psychological disorders in the future (e.g., depression and post traumatic stress disorder).

- **RISK OF EMOTIONAL DISTRESS**: Lack of societal awareness of the risks associated with preterm birth and the extreme close care needed may also cause long-term emotional distress as very little family, friends, and workplace support is provided.

During the infant's hospitalization, most mothers would be under a lot of pressure to balance their other priorities since their infants will be the top priority. These priorities may include taking care of their other children, husband, household, work, and the logistics associated with visiting the NICU. For example, when the author's Twin B expired at the NICU, she had to continue visiting the NICU to see her Twin A. She was unable to healthily grieve as she had to pay full attention and energy to Twin A. Therefore, some women may not have the time or the resources to seek professional help for their emotional distress. That is why, and for the problems discussed above, it will be both economical and medically crucial for the hospital to provide psychological support to the mothers.

Several research studies have proved that providing psychological intervention has better outcomes than not providing it. The author can personally share an example of how the SMC NICU doctors' and

nursing team's emotional care and support has made a positive difference during her experience. Below are summaries of two intervention programs which were found to be effective with mothers of premature infants.

"Trauma Preventative Psychological Intervention"[5]

This program starts with helping mothers recall the traumatic events in order to remember the whole experience in correct sequence. Mothers are also provided with coping and relaxation techniques, solutions for their concerns, and help to improve the support given by their husbands and family. They are also encouraged to discuss their pregnancy history, the current health status of their infant, bonding with the infant, and even addressing any concerns they have about the NICU staff. The mothers meet with the psychologist on a regular basis, an average of twice a week. The psychologist is also available to meet with the mothers daily when things are more intense (e.g., surgery, transfer to another ward). This program's results indicated fewer trauma symptoms.[3] The author believes this is a thorough intervention program which is culturally suitable for Bahrain, as it provides detailed and full resources and support to mothers. In more simple words, it holds the mothers' hands during this difficult time. This would especially be helpful with mothers who are less educated, as it may provide new coping techniques, and help all mothers understand their infants' medical condition in a more simplistic language. The mother of the 29-weeks-premature infant stated:

Use of all the medical terms with us as average individuals at times made things even worse since we were left in the unknown. And believe you me, that's the worse feeling a preemie mother can ever experience, not knowing what is wrong with her precious one and not knowing what the doctors are planning to do, let alone having to sign an approval for the suggested procedure to take place for your little one. We understood that NICU doctors had many patients to take care of and, therefore, many parents to talk to and try to comfort, which logically would leave the doctors very little time for that so important discussion with the parents - a classical dilemma. We needed a psychologist, a person above the nurses but below the doctors, a person that had the time to sit and discuss and explain, a person that could understand the emotions that we were going through, that person who speaks our language.

Moreover, because available information on prematurity, social media support, and self-help strategies is difficult to find in Arabic, this program discussed above will help provide the right tools and information for non-English speaking mothers. Finally, because we lack prematurity awareness in our society, this program will help mothers seek the needed, structured support from their husbands or family.

"Early Preventative Attachment-Oriented Psycho-Therapeutic Intervention Program"[5]

In their intervention, Brecht et al.[5] started with a weekly group therapy session for the parents for a period of five weeks. This was followed by individual therapy for another five weeks. After discharge, the family received one home visit. Finally, three months after discharge, the parents attended a full day training to watch a video to learn proper interaction with their premature child. This module can also be implemented in Bahrain as the parents already attend follow-up sessions for their children with their pediatrician. Therefore, the sessions may be scheduled on the same days of the child's follow-up and should be optional.

RECOMMENDATIONS

- Introduce structured and evidence-based psychological intervention programs, similar to the examples listed above
- If resources do not allow individual intervention programs, group therapy alone can be introduced
- Organize quarterly motivational and educational sessions for new NICU parents,

where successful case studies are presented and risks are explained. Previous NICU parents should also join to either provide support to new parents or receive support from other previous parents

- An on-call therapist should be available to provide support when needed (e.g., loss of an infant, surgery, or severe sudden infant instability)
- Allow religious figures (from any religion) to provide spiritual support in the NICU waiting room
- Previous NICU parents can be trained to volunteer, by leaving their contact details, to become a "mentor" to other parents to provide support and share their experience

CONCLUSION

Preterm birth may cause trauma symptoms to the mother, which may, in turn, lead to long-term problems to the infant and the mother if not treated. Evidence-based intervention programs are recommended during and after the infants' stay at the NICU for better outcomes for both the infant and mother.

*A simple list of questions was provided to two mothers of premature infants born in Bahrain. The questions were sent electronically and were about their experience as a mother of a preterm infant.

References

1. World Health Organisation. Preterm birth.; Accessed 24 Nov 2013. Available from: http://www.who.int/mediacentre/factsheets/fs363/en/index.html.
2. Ministry of Health (Bahrain).Vital statistics, 2012.; Accessed 24 Nov 2013. Available from: http://www.moh.gov.bh/PDF/Publications/statistics/HS2012/PDF/Chapters/CH-03\%20vital\%20stat_2012.pdf.
3. Jotzo M, Poets CF. Helping parents cope with the trauma of premature birth: an evaluation of a trauma-preventive psychological intervention. Pediatrics. 2005;115(4):915–9.
4. Ringland CP. Post-traumatic stress disorder and the NICU graduate mother. Infant. 2008;4(1):14–7.
5. Brecht CJ, Shaw RJ, John NS, et al. Effectiveness of therapeutic and behavioral interventions for parents of low-birth-weight premature infants: a review. Infant Mental Health J. 2012;33(6):651–65.
6. Singer LT, Salvator A, Guo S, et al. Maternal psychological distress and parenting stress after the birth of a very low-birth-weight infant. JAMA. 1999;281(9):799–805.
7. Hoffenkamp HN, Tooten A, Hall RA, et al. The impact of premature childbirth on parental bonding. Evolutionary Psychology. 2012;10(3):542–61.