

Improving neonatal counselling service for premature births

Dear Editor,

Despite the substantial advancement of neonatal care leading to increased survival of infants of periviable gestation, as young as 22 weeks,¹ the anticipated birth of an extremely low gestational age infant remains challenging for both the parents and physician, with regard to decision-making in initiating resuscitation post-delivery. Ideally, the eventual decision should be well informed, ethically sound and mutually agreed upon by the medical team, and alongside parental wishes pre-delivery.^{2,3}

In our hospital, parents facing periviable pregnancies at risk of preterm deliveries (between 23+0 and 24+6 weeks of gestation, without fetal malformation) are counselled by a neonatologist from the High-Risk Consult Team. We conducted a single-centre, cross-sectional study from 1 January 2021 to 1 January 2022, utilising post-neonatal counselling surveys to improve our neonatal counselling service while evaluating the understanding among Asian parents. This study received exemption from the Institutional Review Board.

The counselling sessions, each lasting 30–45 minutes, mostly took place at bedside, in a single to 5-bedded room. Parents were counselled together, occasionally with a family member or friend, on survival rates based on current and subsequent gestations (depending on fetal weight), short-term morbidities (i.e. intraventricular haemorrhage, retinopathy of prematurity, chronic lung disease, necrotising enterocolitis and sepsis), and long-term outcomes (i.e. developmental impairment, cerebral palsy, and hearing and visual impairment). Options of full resuscitation or “comfort care” at birth were discussed. All information was conveyed with simple verbal-only illustrations of the expected outcomes in percentages or ratios. A self-administered questionnaire in English was distributed to parents within 72 hours after the counselling and was collected within 24 hours after distribution.

The questionnaire sought parents’ opinions mainly on the environment in which the counselling took place and the information conveyed by the counsellor (Table 1). Parents were asked to answer each question based on a 5-point Likert scale (1 for strongly disagree and 5 for strongly agree). The answers to the questionnaire were assumed as a consensus between the parents unless the mother was counselled alone. The questionnaire

ended with a text box for any suggestions for a better future counselling session.

We enrolled 20 randomly selected married couples who underwent counselling through purposive sampling. Nineteen mothers were carrying singleton fetus and 1 mother had twins. Enforced COVID-19-related hospital visitation restrictions resulted in half of the mothers being counselled alone. Forty percent of mothers found it helpful to have additional support (family member or friend) during the counselling. Most mothers felt that the sessions were conducted in an appropriate place with sufficient amount of time and were ready to discuss about their baby’s future during the counselling. Ninety percent of mothers understood their baby’s potential outcomes and liked that they were given information on outcomes of prematurity. Most parents (85%) preferred prematurity outcomes to be given in percentages, compared with 50% who favoured ratios and 40% who requested for pictorial guides.

Ninety percent of parents had adequate question-asking opportunities, and 95% of them agreed that our counselling has helped answer questions about their baby. Eighty-five percent of parents decided on the resuscitation plans prior to counselling, and 90% of parents were more confident about their decision post-counselling, with more than half them feeling less anxious post-counselling. Sixty percent of the parents requested for further meetings with their counsellors.

In Asian culture, there are often prenatal birth observances perceived to protect the expectant mother and her unborn child. Expectant mothers are to avoid looking at “unsightly images” and refrain from uttering certain words. Hence, a traditional verbal-only neonatal counselling has been the method of choice in most Asian populations over the last few decades, similar to our study finding. Furthermore, we observed a poor response with regard to visitation to our Neonatal Intensive Care Unit post-counselling, possibly due to fear of what they may potentially witness.

Most parents were satisfied and felt that our neonatal counselling session increased their confidence while reducing their anxiety levels in decision-making for their unborn child. This finding echoed observations in earlier studies, despite the occasional discordance between physician and parents during the decision-making process.⁴ Requests were made from parents to

Table 1. Results of questionnaire from 20 enrolled parents.

1. Settings and environment, no. (%)	Disagree	Neutral	Agree
The meeting place was appropriate	2 (10)	1 (5)	17 (85)
Ready to discuss baby's future	1 (5)	5 (25)	14 (70)
Duration of meeting was sufficient	1 (5)	3 (15)	16 (80)
Preferred additional family member/friend during counselling	0 (0)	12 (60)	8 (40)
2. Information-giving and counsellor approach, no. (%)	Disagree	Neutral	Agree
Understood information provided about baby's outcome	0 (0)	2 (10)	18 (90)
Liked that they were given information about outcomes of prematurity	1 (5)	1 (5)	18 (90)
Preferred that they were given information in the form of:			
Percentages	1 (5)	2 (10)	17 (85)
Ratio	1 (5)	9 (45)	10 (50)
Pictorial guide	5 (25)	7 (35)	8 (40)
Had sufficient opportunity to ask questions about baby	0 (0)	2 (10)	18 (90)
Made decision regarding resuscitation prior to counselling	1 (5)	2 (10)	17 (85)
Felt more confident about decision regarding resuscitation after counselling session	0 (0)	2 (10)	18 (90)
Felt counselling helped answer all questions about baby	0 (0)	1 (5)	19 (95)
Preferred further meetings with counsellor	1 (5)	7 (35)	12 (60)
3. Others, no. (%)	Disagree	Neutral	Agree
Preferred a visit/orientation to the Neonatal Intensive Care Unit	2 (10)	10 (50)	8 (40)
Felt counselling session helped them feel less anxious about baby	2 (10)	7 (35)	11 (55)

highlight positive outcomes like survivors of premature births, expressing the need for “hope” during this difficult period, and for physicians to raise other matters such as “pain and suffering” as well as the financial burden apart from disability and deaths.⁵ In our survey, one parent mentioned that “it would be nice to include some successful cases as examples so that parents know that there may be some hope since all babies are very precious.” This was evident in studies examining parental perception regarding neonatal counselling.⁵⁻⁷

Nevertheless, there is still a knowledge gap within the community regarding babies being born extremely premature. Information given during neonatal counselling may have been misunderstood due to limited health literacy,⁸ leading to increased requests from parents to supplement our counselling with written information or pictorial guides. Parents believe that these tools will further help them decide between active resuscitation versus “comfort care”, and augment their understanding on short- and long-term morbidities.^{4,5,7}

One mother commented, “a pictorial guide on the risks involved at each premature stage would be extremely helpful as it would better allow parents to digest the information overload.” In recent years, there are burgeoning publications in the Western population on supplementing neonatal counselling, either with written material or visual aid to bridge this knowledge gap. Earlier randomised-control studies found that women who were counselled with visual or decisional aids, compared with those who were not, were able to retain the complexity of information regarding potential disabilities of premature babies and anticipated longer duration of hospitalisation, without impacting maternal decisional conflict.⁸⁻¹⁰ So far, to our knowledge, there are no similar studies found in the Asian population.

Our study limitations include small sample size and potential for bias, as most survey forms were completed by expectant mothers alone. Some of the mothers were in labour, thus influencing their decision-making. However, the survey was done fairly soon after the counselling to reduce recall bias. Future implemented post-delivery

survey could gauge if the counselling had prepared them adequately for the arrival of their premature baby.

In conclusion, our traditional verbal-only counselling at the threshold of viability was sufficient in helping parents make decisions regarding their pregnancies. Supplementing future counselling sessions with written materials or pictorial guides could further assist decision-making, improve knowledge gap, and reduce discordance between physicians and parents.

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