Evaluation of a Standard Format for Perinatal Counseling

Abstract
Perinatal Counseling provides an opportunity for neonatologists to discuss prognosis and complications of prematurity with expectant mothers. This study evaluates the effectiveness and satisfaction with a standardized consultation format. 42 surveys were completed by 77 eligible mothers who had perinatal consultation between 19 and 34 weeks gestation. 90% of respondents were satisfied with the amount of influence they had on the treatment provided & 66% were very satisfied with the clarity and amount of information. Our study shows that a standardized format is an effective tool for communicating issues surrounding prematurity, and treatment decisions involved.

Keywords
Perinatal Counseling; Prematurity; Communication; Prognosis; Complications

Background
Perinatal Counseling allows women at risk for preterm birth to learn about the prognosis of and complications faced by their infant [1,2]. Perinatal consultation by a neonatologist also establishes some degree of continuity of care for parents of infants who will be in care for in a complex and intimidating environment [3]. With 11 neonatologists providing this information our institution initiated a standardized form Figure 1 in 2005 for use during perinatal consults. This two page form contains information on pregnancy complications, gestational age, survival, and expected duration of hospitalization of the infant. Complications of prematurity and long term sequelae are discussed in a systems based checklist to ensure that all applicable topics are covered. Specific information regarding prognosis and outcome is individualized on a case by case basis, depending on gestational age, estimated weight and additional risk factors. Though some of the information presented may be forgotten by parents it is hoped that the consultation will allow parents to feel more comfortable with and engaged in the care of their preterm infants.

Objective
This study was undertaken to assess the effectiveness of our perinatal consultation and to evaluate maternal satisfaction with the consultation process.

Design/Methods
After obtaining Institutional Review Board approval and consent from the participants, mothers (aged 18 -35 years, with singleton pregnancies, and no known fetal anomalies) who received prenatal counseling were later interviewed using a structured survey format. Prenatal consults were performed prior to delivery when ordered by an attending obstetrician due to a high likelihood of preterm delivery. Mothers perceptions of the content, tone, and directness of pre delivery counseling and satisfaction with the decision making process were evaluated.

Data were for the mothers, infants, and their outcomes. Questionnaires (Figure 2) were completed by the mothers within a week of the consult. Data was analyzed regarding the content and satisfaction of the counseling process.

Results
Our sample included 42 surveys form 77 eligible mothers. Respondents were between 19 and 34 weeks gestation (all but one were 23-34 weeks), mean gestational age was 28.6 weeks, with a standard deviation of +/- 3.7 weeks. All agreed that they were encouraged to ask questions, and that treatment options regarding resuscitation were discussed. 88% agreed with recommendations for treatment, and 90% were satisfied with the amount of influence that they had on the treatment provided. 83% of mothers wanted full neonatal resuscitation, while 16% preferred treatment only if the infant appeared to be viable. 64% of respondents indicated that decisions regarding treatment of the infant were made jointly by the parents and neonatologists. 14% felt that the decision was made by the neonatologists alone. All stated that their opinions were “somewhat” listened to. 95% were not afraid to ask questions but only 45% asked questions.

Overall 66% were very satisfied with the clarity and amount of information. All respondents stated that that probability of survival was discussed. 92% said that the probability of handicap was discussed, but only 41% felt that newborn suffering was discussed. All felt that the counselors were very caring and 59% described them as extremely caring. Lack of follow up was expressed as the only concern. Of the 16 mothers interviewed following delivery, all were satisfied with the treatment their infant received at delivery. Three mothers included in the study gave birth to infants who subsequently died.

Explanation of long term outcomes and quality of life issues
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Figure 1: Consultation Form.

1. How satisfied are you with the clarity and the amount of information given during the counseling session(s)? (Very satisfied, somewhat satisfied, Not satisfied)
2. a. Were you encouraged to ask questions? (Yes/No)
3. b. Did you ask questions? (Yes/No)
4. c. Were you afraid to ask questions? (Yes/No)
5. d. Do you believe that you were given a choice about whether your infant would be resuscitated? (Yes/No)
6. e. Were treatment choices/options discussed? (Yes/No)
7. f. If yes were you able to voice your preference? (Yes/No)
8. g. Did you agree with the recommendation? (Yes/No)
9. h. Did you say what you wanted? (Yes/No)
10. i. What did you want? (Everything/Treatment if infant looks viable/Don’t know)
11. j. Who made the final decision about the infant’s treatment? (Physician alone/Mother alone/Joint decision)
12. k. Were you satisfied with the amount of influence that you had on treatment decisions? (Yes/No/Somewhat)
13. l. Were you satisfied with the medical care that your infant received at delivery? (Yes/No)
14. m. Were you satisfied with the counseling you received on the days after the delivery? (Yes/No)

Figure 2: Survey/Questionnaire.

1. Was the probability of Survival of your infant discussed? (Yes/No)
2. Was the possibility of your child having a handicap discussed? (Yes/No)
3. Was the possibility or probability of your child experiencing suffering discussed? (Yes/No)
4. How caring was the counselor on a 1-5 scale (5 = most caring)
is important especially in infants at the border of viability [4]. Outcome and Survival data have changed significantly over years [5,6]. Accuracy of survival data has previously been cited as a problem during prenatal counseling [7,8]. Since the time that this study was conducted availability of the NICHD calculator (http://www.nichd.nih.gov/about/org/der/branches/pb/programs/epbo/Pages/epbo_case.aspx) has allowed more accurate prediction of outcomes, and that information has now been incorporated into our consultations. The gestational age, estimated birth weight, gender, number (singleton Vs multiple) and use of antenatal steroids (within seven days of delivery) are used to predict outcomes as closely as possible.

Conclusions

A standardized format is an effective tool for communicating issues surrounding prematurity, and treatment decisions involved. Our results show consistency in the discussion of clinical issues. Follow up to address further questions or concerns may enhance maternal comprehension of these issues. Further feedback from patients may allow the counseling process to be improved upon further enhancing the understanding of the complex issues involved in the birth of a preterm infant.

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