UNIVERSITY OF CALGARY

Does the Antenatal Consultation Meet the Perceived Information Needs

Of the Patient in Preterm or Threatened Preterm Labour?

by

Wendy Helen Yee

A THESIS

SUBMITTED TO THE FACULTY OF GRADUATE STUDIES

IN PARTIAL FULFILMENT OF THE REQUIREMENTS FOR THE

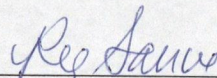DEGREE OF MASTER OF SCIENCE

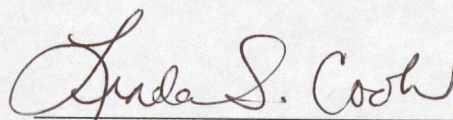DEPARTMENT OF COMMUNITY HEALTH SCIENCES

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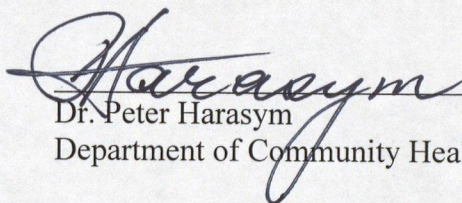# UNIVERSITY OF CALGARY
FACULTY OF GRADUATE STUDIES

The undersigned certify that they have read and recommend to the Faculty of Graduate Studies for acceptance, a thesis entitled "Does the Antenatal Consultation Meet the Perceived Information Needs of the Patient in Preterm or Threatened Preterm Labour?" submitted by Wendy Helen Yee in partial fulfillment of the requirements for the degree of Master of Science.
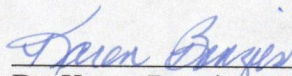
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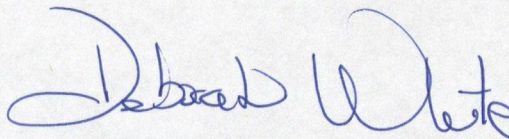Department of Community Health Sciences

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ABSTRACT:

A questionnaire was developed to explore the content, process, social interaction of the antenatal consultation and to identify the information needs of patients admitted in preterm or threatened preterm labour and their anxiety level. A convenience sample of 50 women, between 25 and 32 weeks gestation, admitted to hospital were given the self-administered within 48 hours of the antenatal consultation. The consultation was perceived by 92% of the respondents as helpful to their knowledge and understanding about what might happen to their premature baby and by 78% as helping relieve some of their worry and anxiety. Anxiety levels measured were very high. Respondents' rank order of information needs was chances for survival, medical problems, risk for disability, followed by medical treatments and breast feeding. They wanted physicians to talk more about information that was difficult to understand and issues related to parents' care and interaction with their premature baby.

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1.0 Introduction:

When women are admitted to hospital in preterm or threatened preterm labour, an antenatal consultation with a neonatologist is routinely requested by the obstetricians. The challenge of the antenatal consultation in the setting of preterm labour or threatened preterm labour is that it occurs in the context of an urgent or semi-urgent situation for the patient. Patients are very anxious and concerned about the health outcomes for their infants. There are two patients involved, the mother and the fetus. The immediate health outcomes of the mother and fetus are foremost in the mind of the obstetrician. The role of the neonatologist is to provide consultation regarding the immediate and longer-term health outcomes of the unborn premature infant. It is expected that the information from the antenatal consultation will be used to support shared decisions about the medical treatment of the infant.

The concept of shared decision-making in health care has been evolving since the 1960's. This evolution has required physicians to move away from a strictly paternalistic approach to more open physician-patient interactions. Patients want more information and a shift in the paradigm for physician-patient relationships from a paternalistic to a shared decision making or a patient-centred care model.[1-4] In order for patients to participate in shared decision-making there must be some assurance that they have access to the necessary information. If the role of the physician is to provide that information, then we need to look critically at the delivery of the information and assess whether it meets the perceived information needs of the patient. Information giving is one aspect of the physician-patient interaction that contributes to satisfying patient needs. Roter[5]

describes physician communication to include information-giving, question-asking, partnership-building, rapport-building and socioemotional talk.

The purpose of this study is to explore whether the information content, process and social interaction of the antenatal consultation, as presently provided in the clinical setting, satisfies the needs of patients admitted to hospital in preterm and threatened preterm labour.

2.0 Rationale:

Much of the literature on physician-patient communication originates from the primary care setting, oncology patients seen on hospital wards or in the outpatient clinic.[5,6,7,8,9,10] There is limited evaluation of physician-patient communication in the setting of urgent to semi-urgent consultation by subspecialists. The urgent to semi-urgent consultation usually means that the physician "on call" is asked to see the patient for a first-time encounter. In contrast, in the primary care setting, physicians and patients have an opportunity to interact with one another over repeat visits to develop a physician-patient relationship.

The antenatal consultation by neonatologists to women in preterm labour or threatened preterm labour is an example of an urgent, semi-urgent consultation. This situation usually occurs suddenly and unexpectedly and the women experience significant anxiety and have many questions about themselves and their unborn infant.

The literature suggests it would be reasonable to adopt the model of patient-centred care, providing as much information as the patient desires during the consultations to facilitate shared decision-making by the patient and physician.[1-4] However, implicit in this model is the acceptance that the patient has received and

processed the information so that the information has meaning. Only when the information has meaning can the patient be a mutual partner in decision making.

Roter's[5] work in the primary care setting has led to the development of an organizational framework for identifying communication elements in the physician-patient encounter. The method of Roter's Interaction Analysis System[5] requires audiotaping of physician-patient interactions and categorizing all verbal utterances into defined categories. These categories fall into three functional groupings. The questionnaire developed and used in this study is based on this framework of functional groupings or "domains." In this study, these domains are called content, process and social interaction.

The concept of patient satisfaction has been difficult to define, and remains an uncertain construct, though patient satisfaction surveys have been widely used in attempts to measure quality in the delivery of health care services.[25,26] The word satisfy has many meanings. "To satisfy" as defined in the Webster dictionary[11] includes "to fulfill the need", "to fulfill or answer requirements", or "to free from doubt or anxiety." In this study, I am interested in assessing patient needs in the antenatal consultation. Satisfaction is used to encompass the concept of fulfilling needs for information, the process to provide that information, the social interaction in which that information is delivered and alleviating anxiety in patients encountered during the antenatal consultation.

The literature addressing the information needs of women in preterm or threatened preterm labour as encountered during the antenatal consultation is limited. Studying the perceived information needs of this group of patients and identifying the deficiencies in the current delivery of information during the antenatal consultation can

contribute to our understanding of how this physician-patient interaction can be improved. By improving information delivery in all antenatal consultations, we can optimize patient satisfaction with information provided during the antenatal consultation.

3.0 Background:

The physician-patient relationship forms the basis for the medical consultation. Intuitively one would believe it to be the forum through which a patient presents to the physician his/her symptoms to seek a diagnosis and treatment to correct the symptoms of a disease or condition. The process by which this is accomplished has undergone significant evolutionary change in the last half of the 20th century.

In their essays on this topic, Reiser[12] and Laine[13] trace back the history of the physician-patient relationship to the time of Hippocrates through to the great 19th century physician Oliver Wendell Holmes. In their descriptions, these physicians were authoritative clinicians who assumed that only the physician had the capacity to understand the information and would act in "the best interest" of the patient. In the current model of physician-patient relationships, this is known as paternalism. These sentiments are still prevalent among some physicians today as shown by the study of Elwyn et al[14] who used a focus group of 39 general practice registrars to look at the model of shared decision-making. The registrars reported not being trained in the skills required to involve patients in clinical decision-making. The participants indicated practices that reflected paternalism i.e. "choosing data to help the patient make the decisions you think they ought to make."

Reiser's [12] essay describes how the perspective and the role of patients have evolved since the time of Hippocrates. He suggests that the advent of "technologies of

physical diagnosis" in the first half of the 19th century allowed physicians "the means to gain objective representations of illnesses that bypassed the interpretive distortions of patients." Therefore, rather than having to listen to the patient's expression of their symptoms, technology could be applied to make diagnoses. These technological advances reduced the emphasis on patient input into the diagnostic process of disease and dominated doctor-patient relationships until the second half of the 20th century. Ironically, it was the advent of even more advanced technologies that required the re-entry of the patient's concerns and the opinions of the patients, families and communities back into the equation. This was brought on by the medical ethics movement of the 1960's and the need to consider patient input into the utilization of life support technology. As increasingly expensive technologies arrived, the dilemma of resource allocation also demanded a voice from the patients and families. Patients as health care consumers had a right to be involved in medical decision-making. Reiser also describes the impact of the outcomes movement of the 1980's from which the evaluation of patient outcomes became an integral concept in the selection of competing therapies. Patients now had a right to know about outcomes in order to be able to make informed decisions with their physicians about their care.

3.1 Patient Information Needs

The changing role of the patient led researchers to address the concept of the physician-patient relationship. Emanuel and Emanuel[15] introduced the concept of power relations in physician-patient visits. They outlined four models of the physician-patient relationship (paternalistic, informative, interpretive and deliberative). Since then, others have coined different terms to describe the physician-patient relationship, but the

common themes emerging are that there is a spectrum of power and agenda setting in the physician-patient interaction. Generally speaking, the spectrum ranges from paternalistic to deliberative to informed consent. The deliberative model has been referred to as mutuality, relationship-centered, shared decision-making, or patient-centred model.[6,13,15,16,17,18] The informed consent model has been equated with consumerism.

Whereas Oliver Wendell Holmes advised against giving the patient too much information, studies have shown that although the desire and need for information is not uniform among patients, most patients want more information from physicians. Oken's[19] study showed that as recently as 1961, 90% of physicians surveyed preferred not to tell their cancer patients their diagnosis. By 1979, Novack's[20] study showed that 97% of physicians would tell their cancer patients their diagnosis. Meredith et al[21] studied a group of inpatient and outpatient oncology patients and found that 79% wanted as much information as possible and 96% wanted to know if their disease was cancer. Most wanted to know about prognosis, treatment and side effects of treatment. Blanchard et al[22] studied ward oncology patients and 92% of all patients preferred that all information be given to them. Fallowfield et al[10] studied oncology patients and showed that 95% wanted "as much information as possible, be it good or bad."

3.2 Information and Patient Participation in Decision-Making

Studies show that most patients want more information rather than less information, but how the patients act upon the information given is quite variable. Robinson[23] indicated that although patient preferences for receiving information on treatment and for taking responsibility for treatment varies, patients generally preferred more information to less information. Despite wanting as much information as possible,

24.9% of the oncology patients in Blanchard's study[22] preferred that physicians make the therapeutic decisions and only 69% preferred to participate in making therapeutic decisions. Patients who abdicated decision-making were most often older, sicker males. Strull et al[7] studied hypertensive outpatients and found 47% of their patients preferred the clinician to make therapeutic decisions after receiving all the information. Those who were more highly educated and had more severe hypertension preferred more involvement in therapeutic decision-making. Degner et al[24] studied breast cancer patients and found that younger patients with higher education were more likely to want to be involved in decision-making. The current health status and the severity of the health problem influenced attitudes towards involvement in decision-making. Patients close to life threatening events preferred more passive roles. Degner et al[24] concluded that there may be a difference between the desire for receiving information (the process of information evaluation) and the desire to take responsibility for the treatment decision itself. Physicians appear to be inaccurate in their estimation or understanding of their patients' need for information and their desire for shared decision-making.[7,9,10]

3.3 Patient Satisfaction and Physician-Patient Relationships

Though patient satisfaction is a concept that has been difficult to define.[25,26] the term is commonly used in the literature assessing the quality of physician-patient interactions. It has been used to assess communication problems, patient information needs, patient desires for participation in decision-making, and patient perception of physician behaviour.

Lerman et al[27] studied breast cancer patients in an outpatient setting. Eighty four percent of the patients reported difficulties with communicating with the medical team.

Communication problems were more common if the patient was less optimistic about her disease and had a less assertive coping style and exhibited greater anxiety, depression, anger and confusion. Blanchard et al[8] studied 366 ward oncology patients and their interaction with oncologists during morning rounds. The highly satisfied group tended to be older in age (mean age of patients was 56.7 years), have a poorer prognosis and had received positive quality news during encounters with their physician. Using path analysis for this data, Blanchard[28] identified the following factors as being associated with patient satisfaction: perception of needs addressed that day, emotional support given by the physician, older age of the patients and the physician discussed treatment with the patient. Gattellari et al[9] studied a group of cancer patients presenting for a first consultation with the oncologist. Patients were asked, prior to the consultation, about the degree of involvement they expected in making therapeutic decisions about their care. The consultation was recorded and the degree of involvement of the patient in decision-making was compared to their originally stated expectation. The patient's "perceived role" predicted their satisfaction with the consultation overall, their satisfaction with the amount of information they received, and the emotional support they received. Those who perceived a shared role in decision-making were most satisfied. Those less satisfied perceived the doctor as making the decision or themselves making the decision. Hickson et al[29] studied patients who had made malpractice claims following perinatal injury to their infant. The parents expressed dissatisfaction with physician communication, citing physicians did not warn them about longterm neurodevelopmental problems (70%), physicians attempted to mislead them (48%), physicians would not talk openly (32%) or physicians did not listen (13%).

Ong et al[30] have indicated that the social behaviour of the physician in physician-patient encounters is important to the patients' perception of satisfaction. The authors emphasized the importance of the affective quality or the "tone" of the consultation and the non-verbal aspects of communication. Strauss[31] in describing the consultation with parents' of a child with cleft lip and palate identified the parents as wanting the consultant to be supportive and "make them feel better." Blanchard's[8] study of ward oncology patients also showed that even in the face of poor prognoses, patients wanted physicians to demonstrate kind social behaviours. Patient perception accounted for a greater percentage of the variance in satisfaction than did the observed physician behaviour. Innui and Carter[32] suggested that patient satisfaction is maximized when the physician deals with patient expectations and concerns, communicates with warmth, interest and concern and when the physician provides information to the patient. Perception of emotional support or needs being met seemed most directly related to satisfaction. This parallels the theory of Wortman[33] that information is important as it serves as a means of support and relates to the perception of emotional support or needs addressed.

It is not clear whether having information or the lack of information contributes to an individuals' satisfaction in all situations. The literature would suggest that it depends on the circumstances. Generally speaking, patients want more information "good or bad", but in some situations with elderly persons and advanced disease with poor prognosis, it would appear that less information is desired.[21] Miller[34] has described that persons with avoidance coping styles fare better when provided with lower levels of medical

information. They are more satisfied with the physician-patient encounters in these situations.

Stewart's[35] review of physician-patient communication studies and health outcomes concluded that "effective communication exerts a positive influence not only on the emotional health of the patients, but also on symptom resolution, functional and physiologic status and pain control....Agreement between patient and physician about the nature of the problem and the course of action appears to bode well for a successful outcome." Her review of the literature suggests that health outcomes, not just patient perceptions or satisfaction are positively affected by good physician-patient communication.

3.4 Anxiety and Patient Perception of Information Needs

Anxiety is a person's subjective feeling of tension, apprehension, nervousness or worry that can be brought on by stressful or unfamiliar situations associated with fear of the unknown, fear of potential harm or negative outcome. Patients encounter physicians in such situations as their symptoms of illness may result in diagnoses that are unfamiliar or represent potential harm to their well-being with negative outcomes. Investigators have studied the association between the level of anxiety in patients and their perception of information provided during physician-patient interactions.

In Fallowfield's[36] study, patients who perceived the amount of information given about diagnosis and treatment options as inadequate, showed measurable anxiety and depression. Bertakis et al[47]found that better informed patients were more likely to be satisfied and less anxious. Miller[34] suggests that patient preferences on their information needs can influence their responses to its provision, and that those given information who

prefer not to have it may suffer greater anxiety in decision-making than in the absence of such information. Lerman et al[27] showed that in patients who expressed communication problems with physicians there was an association with greater patient anxiety, confusion, depression and anger. In Gattellari's study,[24] patients whose preferred and perceived degree of participation were congruent in physician-patient encounters involving decision-making had greater decrease in anxiety level post-consultation.

3.5 Risk Communication

The practice of medicine is beset with uncertainty and yet patients want to know about their risks for diseases, complications of diseases, complications of treatment and different outcomes. Patients also need to know these risks so that they can participate in shared decision-making about management of their problems. However, it is unclear from the literature how risk can be most effectively communicated to patients. Risk communication adds another level of complexity to the task of providing appropriate information to meet the patient's perceived information needs.

There are studies to suggest that qualitative or descriptive expression of risk is better understood and preferred by patients.[38,39,40] In a study by Freeman et al,[41] mothers indicated that they preferred risk information concerning a hypothetical vaccine given in numerical terms, whereas the physicians in the study predicted a qualitative or descriptive expression would be preferred. Grimes and Snively[42] concluded that numerical risks were better understood if given as rates rather than proportions. Malenka et al[43] showed that patients were more likely to react to information presented as a relative risk versus an absolute risk. O'Connor[44] studied cancer patients and indicated that positive framing (probability of survival) led patients to focus on quantity of life whereas negative framing

(probability of mortality) led patients to focus on quality of life in decision-making. Kalet et al[45] showed in the primary care setting and Lloyd et al[46] in the pre-surgery setting that patients overall had poor recall of risk information given to them. Bogardus et al[47] suggested that given the variability in patient perception of risk information, in addition to expressing risk numerically or descriptively, consideration should be given to expressing risk through graphic display or relating medical risks to known everyday non-medical risks.

3.6 Differences in Perceived Needs for Information

The type of information that patients may perceive as important may differ from the physicians. Strauss et al[31] studied patient satisfaction with being informed that their child had a cleft lip and/or palate. Parents wanted more opportunity to talk and to show their feelings and wanted physicians to try harder to make them feel better. They also wanted physicians to give more information about the possibility of mental retardation. This highlights the fact that patients may come with misconceptions that need to be clarified. Additionally, physicians can seriously underestimate the information needs of the patients. Perlman et al.[48] interviewed 61 parents of sick neonates, one to three days following the first parent-physician conference after admission of the baby to the Neonatal Intensive Care Unit (NICU). The purpose was to ask the parents to recall the content of the conference with the physician, to evaluate their satisfaction with the conference and to ask about their perceptions of their own information needs. Perlman had the neonatologists complete a questionnaire after the parent-physician encounter to describe what information they had provided during the parent–physician encounter and to identify the information they considered most important to the parents. The parent-

physician encounter was audiotaped. The physicians concentrated on information on diagnosis and identified prognosis as the most important information for the parents, yet due to significant uncertainty, prognosis was often not discussed in great detail. The parents recalled information on current management in greatest detail. Diagnosis and prognosis was secondary. It was most important for them to know "what they are doing to my baby now." Perlman concluded that parents' emphasis on the various categories of information differs from that of physicians. The parents of critically ill neonates were particularly helped by concrete and specific information about management, rather than information about prognosis and diagnosis perceived to be important by the physicians.

3.7 Information and Parents of the Premature Infant

Brazy et al [49] studied a group of parents whose infants were in the NICU. They identified apparent barriers to learning in parents pre-delivery being maternal medications, the urgency of the delivery, pain and stress. She identified that "Barriers that were appreciated by the parents in retrospect included not knowing what questions to ask, not knowing what was really important and the seeming unreality of the whole situation. Parents expressed frustration in the realization that there were some questions to which the answers simply did not exist, such as why the mother went into premature labour and whether the baby will live."

Brazy's group of parents with infants in the NICU reported spending an average of 10-20 hours a week searching for information about premature babies from many resources. Therefore, it would appear that the "information gap" can never be completely closed or satisfied for parents of NICU patients. It is not clear if this seeking of

information was searching for new information or searching for information to verify or refute information that they had already received.

In summary, patients are more satisfied with physician-patient interactions if they receive more information, if the communication process with the physician is open and the physician listens to the patient and if the physician is perceived to provide emotional support. The concept of patient information needs and their satisfaction with the physician-patient interaction are interrelated and enhanced if the patient is less anxious, older, more ill and the patient's perception of degree of involvement in decision-making meets their expectations.

3.8 Communication and the Antenatal Consultation

The essence of the problem in the patient-physician interaction is successful communication. But what exactly is "communication"? Frey, Botan, Friedman and Kreps[50] define communication as "the management of messages for the purpose of creating meaning". Forsdale[51] suggests that there are three related processes constantly at work in communication. These processes are known as the selective processes and involve selective attention, selective perception and selective memory. A theory to explain the workings of these processes is the uses and gratification approach described by Davison, Boylan and Yu: "According to this theory...we will attend, perceive, and remember information that is pleasurable, or that will in some way help to satisfy our needs. This information may or may not be in accord with our existing ideas, but we will attend to it if we expect it to be useful or think that it will give us satisfaction."[41]

Perception occurs in contexts. The Health Belief Model put forth by Hochbaum in 1958 describes the relationship between individuals perceptions in a given context and

the likely health behaviour that follows based upon that perception. The Health Belief Model is a value expectancy theory, which states that an individual's behaviour can be predicted based upon certain issues that an individual may consider (i.e. perceived susceptibility, perceived severity) when making a decision about a particular behaviour concerning their health (from Glanz et al)[52]

A prerequisite step in the logical sequence to achieving the shared decision-making model requires that we are sure that the mechanism by which physicians deliver the information (message) so that it can have meaning for the patient and is relevant to the information needs of the patient. The mechanism encompasses the content, process and social interaction in delivering the message. Relevance to the patient must take into consideration the context within which the patient is receiving the information, as this will determine how they receive and perceive the information. Successful delivery of the information is a necessary condition for a shared decision making interaction between patient and physician.

If the shared-decision (patient-centred) model seems "reasonable" do we actually apply it in practice in the context of a potentially emotionally laden urgent consultation in preterm labour or threatened preterm labour? How well do physicians deliver the information? What information is most important to patients at this time? How well do physicians estimate the information needs of the patients? Do patients understand the information and feel empowered to ask questions of the doctor? Are physicians perceived as supportive by the patients? These are a few of the questions that could be asked about information giving during the antenatal consultation.

A review of the literature did not identify any questionnaires that had been designed specifically for this patient population of women in preterm or threatened preterm labour to address their information needs. Zupanic et al[53] developed a questionnaire, given to 49 women, which encompassed obstetrical and neonatal information. However, their objective was to primarily address the issue of information needs for decision-making in the situation of preterm labour. Paul et al[54] developed a questionnaire concerning the antenatal consultation, but administered it to 67 mothers one week prior to the discharge of their baby from the NICU, following an average NICU stay of 40 days.

This project explored the components of the antenatal consultation that might impact on the patients' perception of acquiring knowledge and understanding about their potentially premature baby. The components of the consultation investigated were content, process and physician social interaction. The type of information perceived as important by the patient was assessed.

If we can identify important patient perceptions arising from the antenatal consultation, then we can further explore the determinants that give rise to these perceptions. This information can be further incorporated into educating current physicians and physicians-in-training toward better communication strategies in the context of urgent and semi-urgent consultations for women in preterm and threatened preterm labour.

4.0 Objectives/Research Questions:

The primary objective of this study was to assess whether the antenatal consultation meets the perceived information needs of women admitted to hospital with

preterm or threatened preterm labour. A second objective was to assess the level of anxiety experienced by these women admitted with preterm and threatened preterm labour. A third objective was to determine if a change in the clinical context (namely 48 hours after the birth of the preterm baby) affected the patient's anxiety state and the recalled perception of the antenatal consultation

To meet these objectives, the following research questions were explored.

1. Did women admitted to the Foothills Medical Centre (FMC) with preterm or threatened preterm labour between 25 to 32 weeks gestation perceive that the information provided in the antenatal consultation

   a. helped their understanding and knowledge about their situation and their baby's condition?

   b. helped relieve some of their worry and anxiety over their baby?

2. What type of information (medical, treatment or prognosis) did the patient **want to hear about** during the antenatal consultation?

3. What type of information (medical, treatment or prognosis) **recalled from the consultation** by the patient was perceived to be most important to them?

4. What was the level of anxiety experienced by the patients admitted with preterm or threatened preterm labour at 25 to 32 weeks gestation, following an antenatal consultation; as measured by the Spielberger State-Trait Anxiety Inventory (STAI)?

5. Did the patient's anxiety state and her recalled perception of the antenatal consultation change 48 hours after the birth of the preterm baby?

5.0 Methods:

5.1 Study Design

This was an exploratory descriptive study using a cross-sectional survey of a convenience sample of women presenting to the Foothill Medical Centre and admitted with preterm labour or threatened preterm labour between 25 and 32 weeks gestation. The patient was asked to complete a questionnaire within 48 hours of the antenatal consultation if she had not delivered by then. If delivery occurred within a week of the antenatal consultation, the patient was approached at 48 hours after the birth of the baby to complete an abbreviated questionnaire comprised of two sections of the original questionnaire.

5.2 Location of the Study and Study Enrolment

The Foothills Medical Centre is the regional tertiary care facility providing tertiary care obstetrics and tertiary care neonatal intensive care to all of southern Alberta and southeastern British Columbia. There are generally 4,000 deliveries per year at this centre and of these deliveries, approximately 200 per annum are infants born at less than or equal to 32 weeks gestation. High risk pregnancies and preterm deliveries are managed at this site and time permitting, neonatology is generally asked by the obstetrical service to see women who are at high risk for preterm delivery, to provide an antenatal consultation. This consultation service is available 24 hours a day, 7 days a week on an urgent, semi-urgent basis.

Each day the attending neonatologist was contacted by the investigator to ask if she/he had seen any patients for antenatal consultation in the preceding 24 hour period. Neonatologists also called the investigator to indicate that they had seen patients eligible

for the study. The investigator identified these patients on the antepartum unit or labour floor within 48 hours of the initial antenatal consultation and approached them to explain the study. After the patient gave signed informed consent, a questionnaire was left with the study participant with a self-addressed return envelope. They were given instructions to complete the self-administered questionnaire and return it to the investigator in the addressed envelope. Most questionnaires were returned within a week to 10 days. Eleven non-respondents were not re-approached or given reminders to request completion of the questionnaire. The study participants were recruited in the period from March 2003 to September 2003 by the investigator.

The neonatologists were aware that the study would require the patient to answer a questionnaire about the antenatal consultation, but they were not aware of the content of the questionnaire.

5.3 Ethics Approval

This study was approved by the Conjoint Health Research Ethics Board of the Calgary Health Region and the University of Calgary. It had also received administrative approval from the members of the Calgary Health Region Division of Neonatology, and Department of Obstetrics and Gynecology.

5.4 Study Population

The study population of interest was the group of women presenting and admitted to the FMC with preterm labour or threatened preterm labour between 25 and 32 weeks gestation, and then seen by the neonatologist for antenatal consultation. The study did not include patients at 23 or 24 weeks gestation whose antenatal consultations would have involved complicated decision-making regarding resuscitative interventions for the fetus

at the margins of viability. The antenatal consultation occurred following a request from the obstetrical service and was conducted by the neonatal specialist (the attending neonatologist, or delegate) from the neonatal team on clinical service for the NICU at the time of the request for the consultation.

Inclusion criteria:

1. Women presenting and admitted to FMC with preterm or threatened preterm labour between 25 and 32 weeks gestation and seen by neonatology for antenatal consultation at the request of obstetrics.

2. Women admitted with preterm or threatened preterm labour between 25 and 32 weeks gestation, with or without rupture of membranes, whose medical status permitted them to speak with the consultant neonatologist.

3. Women whose understanding of English was adequate to complete the questionnaire.

Exclusion criteria:

1. Women admitted with preterm labour between 25 to 32 weeks gestation who delivered prematurely before they had an opportunity to complete the questionnaire.

2. Women admitted with preterm or threatened preterm labour between 25 and 32 weeks gestation whose medical status did not permit completion of the antenatal consultation by the neonatal specialist.

3. Non-English speaking women.

4. Women in preterm or threatened preterm labour at gestational ages 23 -24 weeks.

5. Women seen by the investigator as the neonatal consultant when serving as the attending neonatologist on service for the NICU.

5.5 Measures

The composite questionnaire was comprised of three parts. (Appendix A)

Part 1– was the antenatal consultation questionnaire (ACQ), designed to explore

patient satisfaction with the three domains of the consultation.

Part 2– was the Spielberger State-Trait Anxiety Inventory (STAI).[55]

Part 3 – was a questionnaire designed to capture patient characteristics and

sociodemographics.

5.5.1 The Antenatal Consultation Questionnaire (ACQ)

A questionnaire (ACQ) was designed to identify the type of information that was

given to patients in preterm or threatened preterm labour during the antenatal consultation

and their perception of that information. The ACQ was developed to explore patient

satisfaction with three domains of the consultation, namely 1) content - type and amount

of information given; 2) process - how the information was given; and 3) social

interaction - physician demonstrates emotional support, permits patient to express

feelings. The domains were created to try and capture the essence of the antenatal

consultation based on Roter's conceptual groupings of physician communication

categories.[5]

The ACQ addressed the three domains of the consultation, guiding the patient

through the domains to facilitate her recall and evaluation of the different components of

the consultation. Having had an opportunity to review each of these domains, the patient

was then asked to rate the consultation overall in helping her perceived acquisition of

knowledge and to inquire about the information that was most important to her. As

audiotaping of the physician-patient encounters was not done in this study, the

questionnaire had to capture the essence of the consultation to guide and cue the patient's recall of the discussion that had occurred with the neonatal specialist within the preceding 48 hours.

In the first domain, the Content of the Consultation (CC) there were 9 questions with two components. The first part of the question asked if the patient had received information on a certain topic. If they answered yes to the first part they were cued to answer the second part of the question which asked if they were satisfied with the amount of information given; answered on a 5-point Likert scale anchored by strongly disagree to strongly agree. The last question in this domain asked on a 5-point Likert scale if they were satisfied with the total amount of information given. The next domain, the Process of the Consultation (PC) was comprised of ten statements that were scored on a 5-point Likert scale anchored by strongly disagree to strongly agree. A sample statement from this domain would be "The neonatal specialist asked if I understood the information being discussed." The final domain of the antenatal consultation questionnaire, the Social Interaction in the Consultation (SI) began with asking if the neonatal specialist introduced himself/herself. This was followed by nine statements that were scored on a 5-point Likert scale anchored as in the other domains. A sample statement from this domain would be "The neonatal specialist made it easy for me to talk about what I was worried about." Higher scores represented positive, favorable assessment of the consultation.

The Likert scale was first developed by Rensis Likert in the 1920's[56] An item in a Likert scale is presented as a statement which is followed by response options that indicate varying degrees of agreement with or endorsement of the statement. The number of response options can be even or odd ranging from the response that most strongly

opposes the statement to the response that most strongly endorses the statement. These ends of the response scale are referred to as the "anchors" and represent polar opposite responses. It is noted that if one uses a scale with an odd number of responses the middle response represents a neutral position, whereas using an even number of responses forces the respondent to choose a side and declare an opinion on the statement. If numeric values are attached to the responses, the responses can be summed to give a scale score. In this study, the Likert responses offered in the questionnaire were "strongly disagree, disagree, unsure, agree, strongly agree" and the responses were assigned numeric values from 1 to 5. The Likert scale is widely used in instruments that measure opinion, attitude or beliefs.[57]

The last page of the ACQ asked the participant to respond to two statements on a 5-point Likert scale. The first statement (RC-1) was "The consultation provided information that helped my understanding and knowledge of what could happen to my baby if he/she was born prematurely." The second statement (RC-2) was "The consultation was helpful in relieving some of my worry and anxiety over my baby." The participants were then asked to identify the information they **wanted to hear about** during the consultation and the information they **remember being most helpful** to them after the consultation, by rank ordering five options. Lastly, they were given two open ended questions to describe information they would have liked to hear about or topics in which they would have liked more information on.

5.5.2 Piloting the ACQ

A preliminary questionnaire was piloted on a convenience sample of five mothers whose infant's were patients in the NICU, to obtain feedback on the content, the

composition, the comprehensibility and the length of the questionnaire. The questionnaire was designed to be self-administered, but in the pilot the questionnaire was administered to the mother by the investigator. The questions were answered as the investigator read each question out loud while the mother followed along with her copy. The mothers were asked for feedback on the questions as the questionnaire progressed and at the end of the questionnaire. The total questionnaire required twenty five to thirty minutes to complete when given orally by the investigator. The mothers all agreed that it would take less time self-administered. Modifications to the questionnaire were made following the pilot. Notably, the respondents advised that negatively framed questions be rewritten to be positively framed. The items about information on visiting in the NICU and the role and the availability of the neonatal team were also added.

While piloting the questionnaire, some couples were seen together and the feedback was that couples preferred to answer the questionnaire together. As a result there were no specific inclusion or exclusion criteria set forth for fathers to answer the questionnaire separately from the mother. The questionnaires were usually left with the mother as fathers were not consistently present when the patients were approached by the investigator to explain the study. Respondents were given a place on the questionnaire to indicate who had participated in answering the questionnaire.

The questionnaire was then sent to five external neonatologists (three provided feedback), three neonatal nurse practitioners and two NICU nurses as content experts for face and content validity assessment.

5.5.3 Spielberger State-Trait Anxiety Inventory (STAI)

Patients were asked to answer a widely used, validated, reliable anxiety scale as studies have shown that anxiety states correlate with patient perception of successful communication in physician-patient encounters.

The first version of the STAI was developed by Charles Spielberger in 1970 and the most recent version was modified in 1981.[55] Anxiety states are characterized by subjective feelings of tension, apprehension, nervousness, and worry. Trait anxiety refers to relatively stable individual differences in anxiety-proneness, that is, to differences between people in the tendency to perceive stressful situations as dangerous or threatening and to respond to such situations with elevations in the intensity of their state anxiety reactions.

The S-Anxiety scale (STAI Form Y-1) consists of twenty statements, rated on a 4-point Likert scale, that evaluate how the respondents feel "right now, at this moment." The T-Anxiety scale (STAI Form Y-2) consists of twenty statements that assess how people "generally feel." The STAI-Y S-Anxiety and T-Anxiety scales are printed on opposite sides of a single-page test form. The S-Anxiety scale is always administered first, followed by the T-Anxiety scale. This order is recommended when both scales are given together. Since the S-Anxiety scale was designed to be sensitive to the conditions under which the test is administered, scores on this scale can be influenced by the emotional climate that may be created if the T-Anxiety scale is given first. In contrast, it has been demonstrated that the T-Anxiety scale is relatively impervious to the conditions under which it is given.

The theoretical range of scores is between 20 and 80 for each scale, based on a 4-point Likert score on 20 items each for the state anxiety score and the trait anxiety score. Higher scores represent greater anxiety. There are no identified clinical cut-offs for referral of high scores.

The STAI norms for working adults are based on 1,838 employees of the Federal Aviation Administration (1,387 males; 451 females). Although most were white-collar workers, the sample was heterogeneous with regard to age, education and occupation. Norms are subdivided by three age groups (19-39, 40-49 and 50-69 years) and by gender. Norms are also available for samples of college students, high school students and military recruits, but not for pregnant women.

Cronbach's alpha for the state-anxiety score for females age 19 to 39 years is reported as 0.93 and ranges from 0.86 to 0.94 across sample groups of working adults, college students, high school students and military recruits of both genders. The Cronbach's alpha for the trait-anxiety score for females age 19 to 39 is 0.92 and ranges from 0.89 to 0.92 across sample groups of working adults, college students, high school students and military recruits of both genders.

Concurrent validity in the development of the trait-anxiety score was demonstrated by correlations between this score and the IPAT Anxiety Scale (Cattell and Scheier 1963) and the Taylor Manifest Anxiety Scale (Taylor 1953) measured in a sample of college students and a sample of neuropsychiatry patients. Correlation values ranged from 0.76 to 0.83. Correlation of the state-anxiety score and the trait-anxiety scores with the Cornell Medical Index with a correlation of 0.70 indicated that a large number of medical problems were associated with high anxiety scores on both subscales.

Construct validity of the state-anxiety score has been demonstrated by higher scores in military recruits tested shortly after they began a highly stressful training program compared to college and high school students of about the same age who were tested under relatively non-stressful conditions. The state-anxiety scores of the recruits were also higher than their own trait-anxiety scores, suggesting higher state anxiety related to the training event. In contrast, the mean state-anxiety and trait anxiety scores for normal subjects tested under non-stressful conditions were quite similar. Construct validity was further demonstrated for the state-anxiety scale under experimental conditions for a group of college students. They were asked to complete the STAI when exposed to four experimental conditions: 1) normal classroom situation, 2) ten minutes into an exam situation, 3) following exposure to stressful images and 4) following a ten minute period of relaxation. The scores were lowest following the relaxation period and progressively increased from normal situation, to exam situation, to post viewing of stressful images.

In Zupanic's study[53] the mother's in preterm labour had a median state anxiety score of 44 placing them at the 77th percentile.

5.5.4 Sociodemographic Characteristics

The third part of the questionnaire was designed to capture sociodemographic characteristics of the respondents and to identify the general health and pregnancy-related health conditions of the women admitted in preterm labour and threatened preterm labour.

5.5.5 Post-Delivery Questionnaire

The patient was advised that after the birth of the baby, if this occurred within 7 days of the antenatal consultation, she would be asked to answer a second questionnaire which was an abbreviated version of the first questionnaire. This abbreviated questionnaire (Appendix B) comprised of the last page of the ACQ, relating to the overall rating of the consultation with the open-ended questions, and the Spielberger STAI.

Re-administration of the questionnaire 48 hours after the birth of the infant was designed to assess if the patients' recalled perception of the antenatal consultation and their anxiety state differed with a change in the contextual situation, namely following the birth of the infant.

5.6 Sample Size

The exploratory nature of this descriptive study did not lend itself to an estimate of a critical effect size. The aim was to describe the perceptions of women relating to acquisition of understanding and knowledge following a physician-patient interaction and to describe the information they perceived as being most important to them. However, there was no attempt to measure this before and after the event. Consequently, a formal sample size and power calculation was not feasible in this study. A convenience sample of fifty was used for the study. Similar sample sizes were used by Perlman[39] in her study of parents of NICU patients within the first few days of admission of the baby to the NICU, Zupanic[53] in his study of parents counseled for impending preterm delivery and Paul[54] in his study of mothers of NICU babies one week prior to discharge from the NICU. Perlman interviewed 61 parents of 43 infants, Zupanic had 49 patients who

responded to a self-administered questionnaire and Paul's questionnaire was answered by 67 mothers.

5.7 Analysis

The analysis was conducted in three stages. First, an analysis was carried out to obtain descriptive statistics to characterize the study sample. The data were described as frequencies, percentages, means and standard deviations and distributions were demonstrated by boxplots with medians and interquartile ranges. In order to compare the responses to the questionnaire, subscale scores were derived for each of the three domains of the questionnaire, Content of Consultation (CC-TOT), Process of the Consultation (PC-TOT) and Social Interaction during the Consultation (SI-TOT). Subscale scores were derived for each of the three domains of the questionnaire from the sum of the Likert scores. Student's t-tests were used to compare the means for the Likert scores and STAI scores obtained from mothers and fathers or couples answering the questionnaires. The internal consistency of each subscale was assessed by calculating the Cronbach's alpha for each.

Cronbach's alpha is an assessment of the internal consistency of a scale. A scale is internally consistent to the extent that its items are highly inter-correlated. High inter item correlation suggests that the items are all measuring the same thing. A scale's alpha is influenced by the extent of the covariation among the items and the number of items in the scale. An alpha of 0.70-0.80 is considered respectable, and an alpha of 0.80-0.90 is very good. With an alpha >0.95 consideration might be given to decrease the number of items in the scale.[57]

In order to determine the underlying structural relationship of six variables (two patient anxiety and four patient satisfaction) the total scores were analyzed using a principal component analysis with normalized varimax rotation. Specifically, the six variables were the following: (a) two subscales of the State-Trait Anxiety Inventory (State anxiety score [STAT_SC] and the Trait anxiety score [TRAI_SC]), (b) the three domains of the antenatal consultation questionnaire (Content of the Consultation [CC-TOT], Process of the Consultation [PC-TOT], Social Interaction of the Consultation [SI-TOT]) and (c) the Amount of Information (AMT_INFO), which was the number of items that the respondent recalled receiving information on from the neonatal specialist in Content of the Consultation (maximum number of items = 9). The linear interrelationship among the six variables was expressed as a correlation matrix that was input in the principal component analysis.

However, the analysis indicated that the two patient anxiety variables were unrelated to the four patient satisfaction variables derived from the antenatal consultation questionnaire. Therefore, the principal component analysis was limited to five variables derived from the ACQ. These were the following: the three domains of the ACQ (Content of the Consultation [CC-TOT], Process of the Consultation [PC-TOT], Social Interaction of the Consultation [SI-TOT]) and the two summary questions from Rating of the Consultation (RC-1 asking if the antenatal consultation provided information that helped the respondent's knowledge and understanding of what could happen if their baby was born prematurely and RC-2 asking if the antenatal consultation was helpful in relieving some of the respondent's worry and anxiety over their baby).

The main application of principal component analysis[57,58] is to uncover the latent structure of a set of variables and to reduce a large number of variables to a smaller number of factors to explain the variance in the data set with the simplest model. Principal component analysis extracts factors that represent multiple correlated variables. The term variance maximizing (varimax) rotation refers to the computational technique to achieve the goal of rotation of the original variation space, which is to maximize the variance (variability) of the "new" factor, while minimizing the variance around the new factor. Because each consecutive factor extracted is defined to maximize the variability that is not captured by the preceding factor, consecutive factors are independent of each other, uncorrelated or orthogonal to each other.

Principal component analysis[57,58] begins with a correlation matrix of the variables of interest. Each successive factor extracted by this technique account for progressively less variance. The variances extracted by the factors are called the eigenvalues. There are two methods commonly used to decide how many factors to retain. The Kaiser criterion suggests retaining only factors with eigenvalues greater than 1. The scree test of Cattell suggests plotting the eigenvalues graphically and choosing factors whose eigenvalues are above the point where the decreasing values "level off." Once the factors have been extracted it is possible to then look at the correlations between the variables and the factors. These correlations are called factor loadings. Rotational strategies are then used to obtain a clear pattern of loadings, that is, factors that are marked by high loadings for some variables and low loadings for others. A common rotational strategy is variance maximizing (varimax) rotation, which maximizes the variance on the new factor.

Third, a bivariate correlation matrix was generated and used Pearson product moment correlation coefficients to identify associations between the state and trait anxiety scores of the STAI and a composite variable called Grand Total (the total sum of the subscale scores from each of the domains of the antenatal consultation questionnaire) and select sociodemographic characteristics of the study sample. This analysis was done as studies suggest that anxiety is associated with patients who are less satisfied with the information they receive, patients who report communication problems with the physician and patients whose perception of their participation in the physician-patient encounter did not match their expectations.[9,27,36,37] Based on clinical experience, I hypothesized that women with higher risk pregnancies such as multiple gestation, pregnancies resulting from assisted reproductive technologies, advanced maternal age, women with histories of multiple previous pregnancy losses and threatened preterm labour in the presence of ruptured membranes might have higher anxiety levels.

The data was analyzed using SPSS for Windows (Release 11.0, SPSS Inc, Chicago, Illinois, USA) and STATISTICA for the principal component analysis.

6.0 Results:

6.1 Study Population

Between March 2003 and September 2003, 61 women in preterm and threatened preterm labour, admitted to the Foothills Medical Centre were approached to participate in the study. The total number of potential eligible patients was not ascertained. All the patients approached consented to participate in the study. This represents a convenience sample of the eligible patients admitted to the hospital. Fifty questionnaires were completed and returned. Reasons for not completing the questionnaire were delivery of

the baby prior to answering the questionnaire or discharge from the hospital prior to answering the questionnaire. The majority of the respondents were patients on the antepartum unit as it became evident that women in active labour admitted to the labour floor were unlikely to be able to answer the questionnaire prior to delivery.

6.1.1 Sociodemographic Characteristics

The maternal age ranged from 20 to 42 years of age with a mean of 29.7(S.D. 5.4) and the distribution of maternal age is outlined in Figure 1.

FIGURE 1. Distribution of Ages of Women Admitted in Preterm or Threatened Preterm Labour
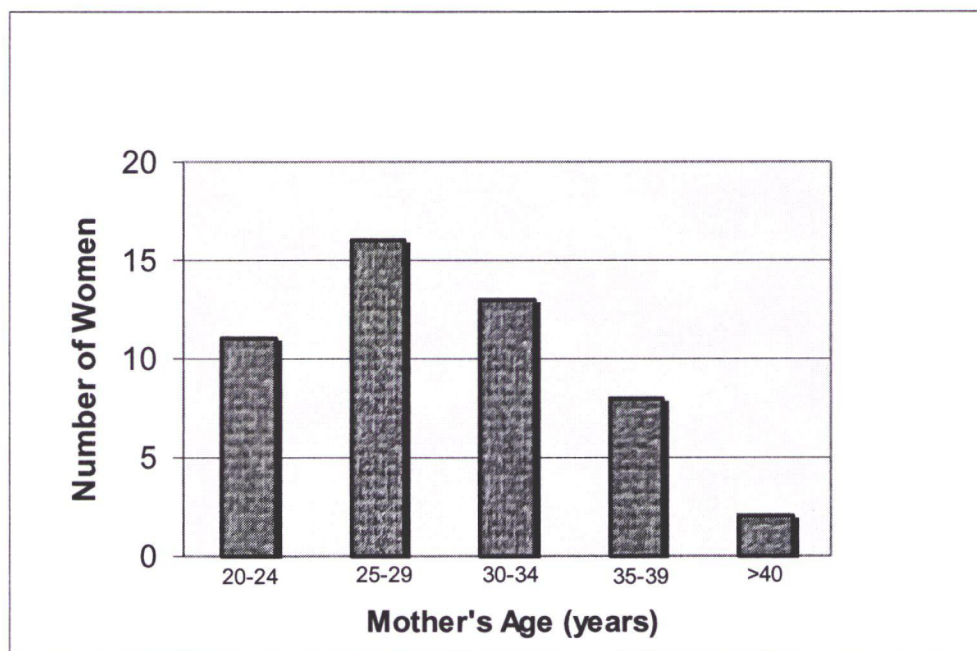
TABLE 1. Sociodemographic Characteristics of Women Admitted in Preterm or Threatened Preterm Labour.

Patient Characteristics	Frequency	Percent
First Language		
English	**41**	**82**
Other	**7**	**14**
Missing data	**2**	**4**
Marital Status		
Single	**4**	**8**
Married	**35**	**70**
Common-in-law	**11**	**22**
Education Level*		
Did Not Completed High School	**5**	**10**
Completed High School	**7**	**14**
Some College/University	**14**	**28**
Completed College/University	**24**	**48**
Total Household Income**		
< $40,000	**11**	**22**
$41,000 - $80,000	**19**	**38**
$81,000 - $120,000	**10**	**20**
> $120,000	**6**	**12**
Missing data	**4**	**8**

n = 50

* For comparison from the 2001 Canadian Census, in the Calgary, Alberta female population age 20-44 years: did not complete high school (13.3%), completed high school (27.8%), trades diploma (8.3%), completed college or university (50.6%)

**For comparison from the 2001 Canadian Census, in Calgary, Alberta: median family income in couple family $71,139; median family income lone parent family $36,835

Sociodemographic characteristics of the sample population are described in Table 1. The majority of the patients were married or in common-law relationships. The overall education level of the sample was high with 76% having some college or university education compared to ~60% in the Calgary, Alberta population as taken from the 2001 Canadian Census.[59] The total household income of the sample was reflective of the Calgary, Alberta population as most of the patients were married or common-law and the median income for couple families in Calgary was $71,139 from the 2001 Canadian Census.[59]

There was a positive correlation between education level and household income and maternal age, with older mothers being more educated and being in a household with higher total income. This information is consistent with expectations. (Figure 2 and Figure 3)

FIGURE 2. Maternal Age by Education Level in Women Admitted in Preterm or Threatened Preterm Labour.
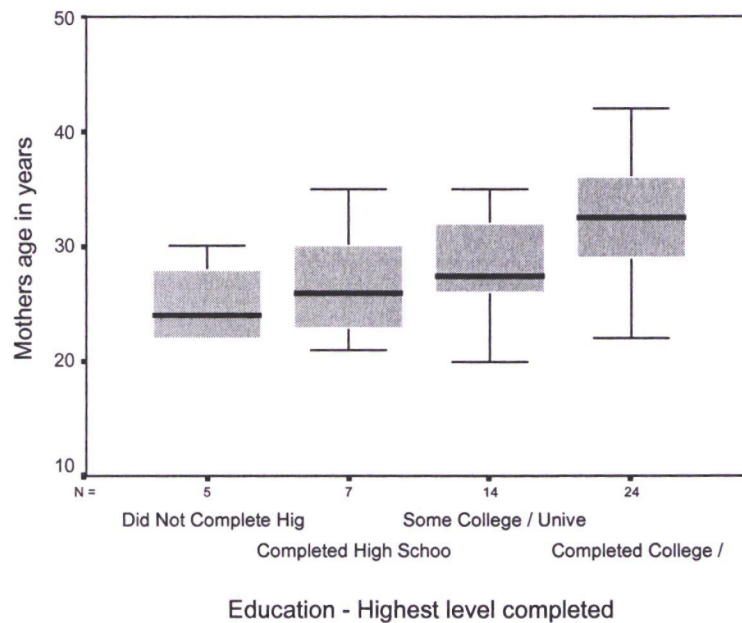
FIGURE 3. Maternal Age by Total Household Income in Women Admitted in Preterm or Threatened Preterm Labour.

Total household income ($thousand)
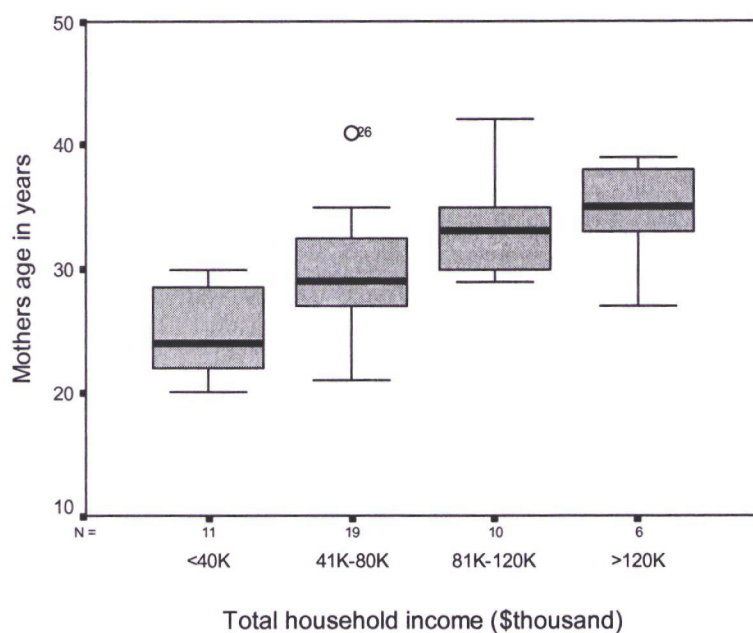
6.1.2 Gestation of Current Pregnancy

The gestational ages of the pregnancies ranged from 24 weeks to 32 weeks with a mean of 28.8 weeks (S.D. 2.4) and the distribution outlined in Figure 4. Eighty percent of the pregnancies were 27 weeks gestation or greater, which would offer an overall good prognosis for survival outcome.

FIGURE 4. Distribution of Gestational Age of Pregnancies of Women Admitted in Preterm and Threatened Preterm Labour
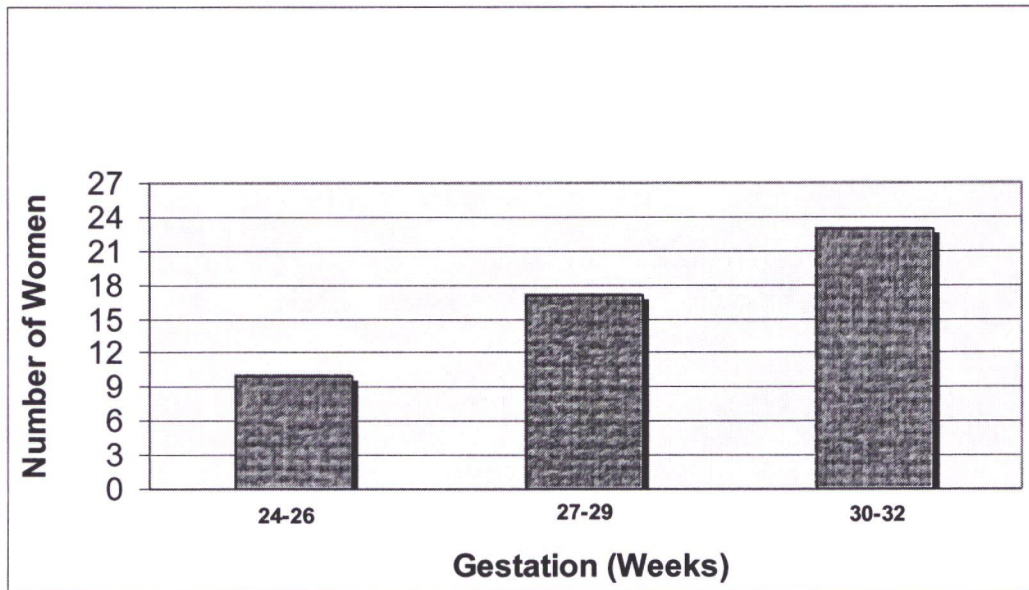
6.1.3 Pregnancy History

This was the first or second pregnancy for the majority of the patients and the majority of current pregnancies were singleton gestations. Fifteen (30%) of the current pregnancies were a multiple gestation with 13 (26%) twins and 2 (4%) triplets. The following figures (Figure 5 and Figure 6) show the gravida and parity status of the women in the study and their obstetrical history with previous pregnancy losses. Fourteen women (28%) conceived with the assistance of reproductive technologies (ART).

FIGURE 5. Gravida and Parity of Women Admitted in Preterm and Threatened Preterm Labour
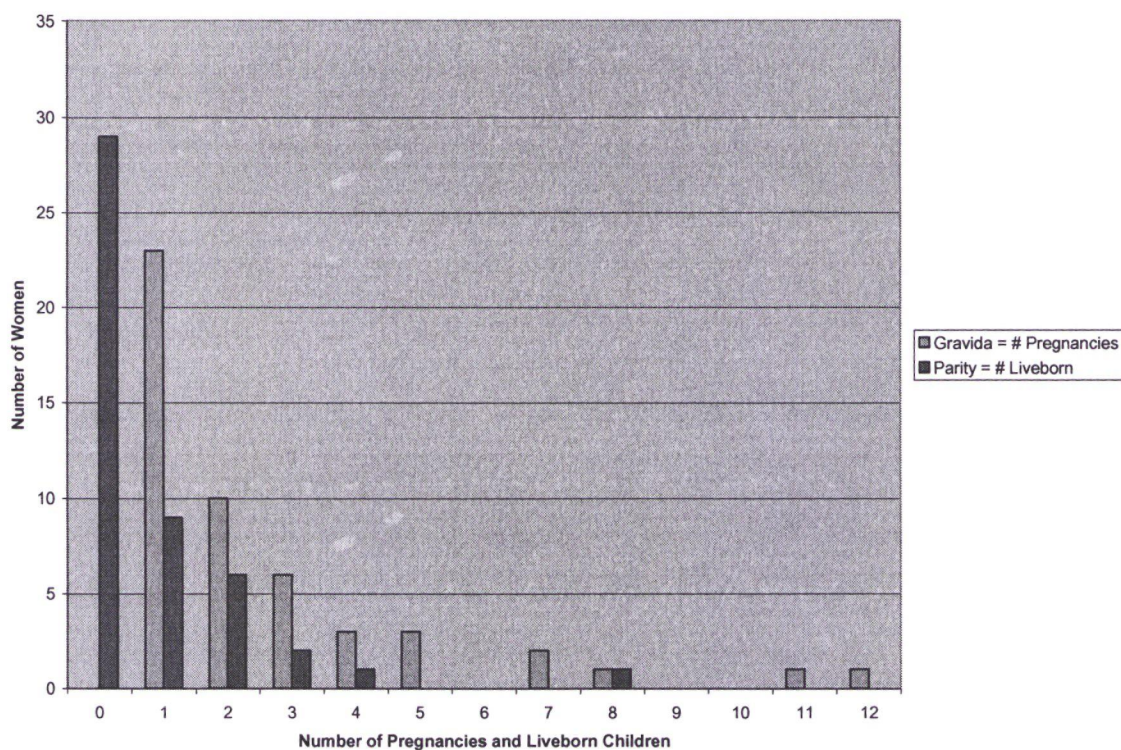
FIGURE 6. Previous Pregnancy Losses of Women Admitted in Preterm or Threatened Preterm Labour
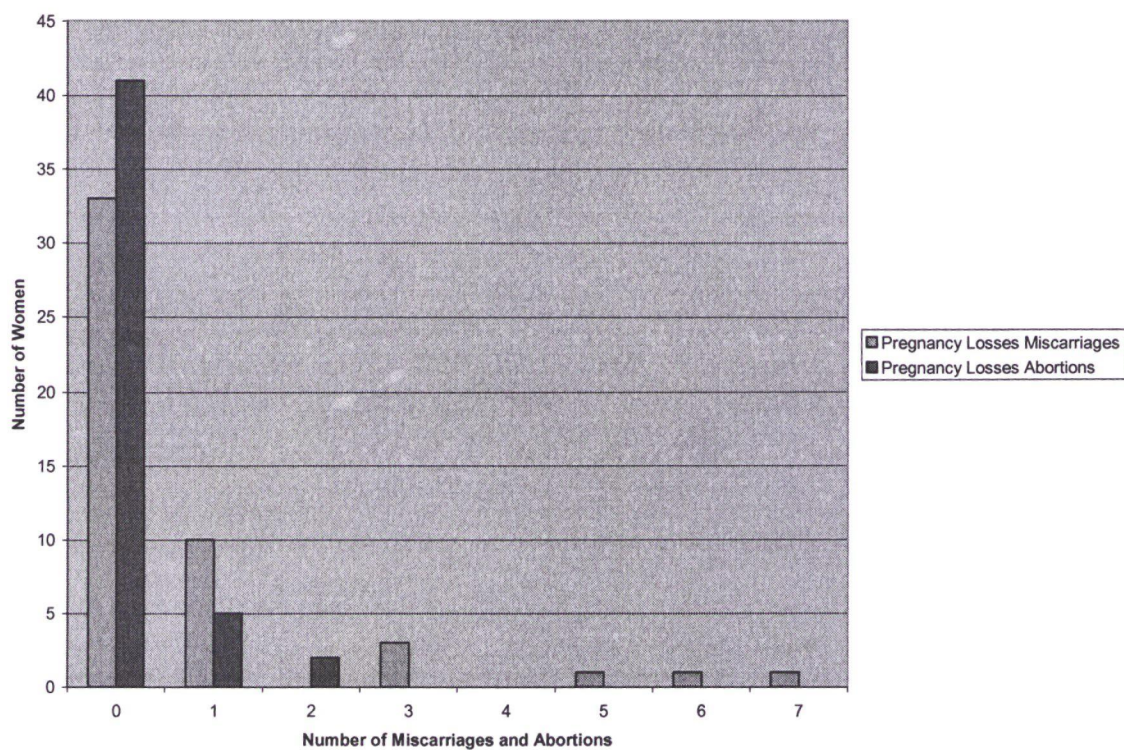
6.1.4 General Health or Complications of Pregnancy

Twenty-four percent of patients were identified as having a common underlying medical condition, 12% had pregnancy-induced hypertension (PIH) and 6% had gestational diabetes mellitus (GDM). The generally quoted incidence of PIH in the obstetrical population is 6-18% and the prevalence of diabetes mellitus in the obstetrical population is 2-3%, with 90% of these identified as GDM.[60] Eighteen percent identified another condition such as migraine, multiple sclerosis, arthritis, back ache, Crohn's disease, agoraphobia, asthma, polycystic ovary and placenta previa, represented by one person with each condition (data not shown).

TABLE 2. Percent of Pregnancy-Related Health Conditions in Women Admitted in Preterm or Threatened Preterm Labour.

Pregnancy-Related Health Conditions*	Percent
Previous stillbirth >20 wks	6
Previous premature <=36 wk	20
Abnormal ultrasound	6
PIH	12
GDM	6
Ruptured membranes	27
Cervical changes	52
Having contractions	18

n = 50
PIH = Pregnancy Induced Hypertension
GDM = Gestational Diabetes Mellitus
* Women could have more than one pregnancy-related health condition

TABLE 3. Percent of Underlying Medical Conditions in Women Admitted in Preterm or Threatened Preterm Labour.

Underlying Medical Conditions*	Percent
High Blood Pressure	6
Diabetes	0
Lupus	4
Thyroid problems	6
Heart condition	2
Kidney failure	0
Depression	4
Seizures	2
Other medical conditions	18

n = 50
* Women could have more than one underlying medical condition

6.1.5 Knowledge about Premature Babies

Twenty percent of the participants had previously delivered a premature baby,

defined as less than or equal to 36 weeks completed gestation. Nevertheless, 66% of

participants reported some previous knowledge of premature infants. Participants

reported that this came from television, friends, newspapers and magazines, the Internet

and family. Each of these sources was identified by twenty percent or more of the

respondents. A small percentage of patients identified the source of information as

coming from work experience, from doctors and nurses, or from information at the

hospital.

6.2 Results of the Questionnaire

Seventy-six percent of the study respondents identified the neonatologist as being

the neonatal specialist who provided the antenatal consultation. Sixteen percent of the

respondents were not sure who they were speaking to and could not distinguish among

the neonatologist, the neonatal fellow or other health care professional from neonatology.

All the respondents agreed that the individual providing the consultation introduced

themselves.

In 58% of the cases, the husband or partner was present at the time of the

consultation. Other persons present and identified were mother of the patient, the nurse or

friends. The respondent to the questionnaire was usually the mother.

TABLE 4. Person Answering the Antenatal Consultation Questionnaire Amongst Women
Admitted in Preterm or Threatened Preterm Labour

Person(s) answering questionnaire	Number	Percent
Mother only	42	84
Father only	2	4
Mother and Father (couple)	6	12

n = 50

The responses to the three domains of the ACQ developed for this study, and the

response to the STAI were analyzed by the subgroup of mothers only (n = 42) answering

and the subgroup of fathers or couples (n = 8) answering. This was done to examine any

differences in responses between mothers and fathers/couples. There was no difference in

the mean scores for the subgroup of mothers only answering compared to the

fathers/couples answering (Table 5 and Table 6), therefore the analysis reported in this

study is based on the responses provided by the 50 respondents completing the

questionnaire.

The subscale scores of the three domains of the questionnaire are presented in

Table 5. The internal consistency of each domain was assessed by calculating the

Cronbach's alpha for each. The Cronbach's alpha for the Content of the Consultation

(CC-TOT) was 0.75, the Cronbach's alpha for Process of the Consultation (PC-TOT) was

0.88 and the Cronbach's alpha for the Social Interaction (SI-TOT) during the

Consultation was 0.82. These were close to the "gold standard" alpha coefficient of 0.80,

suggesting acceptable internal consistency of each of the domains in the questionnaire. In

this study, the Cronbach's alpha for the state anxiety score was 0.89 (published alpha

coefficient for age and gender group 0.92)[55] and for the trait anxiety score was 0.92

(published alpha coefficient for age and gender group 0.93).[55]

TABLE 5.Comparison of Mother's and Father's/Couple Response in each Domain in the
Antenatal Consultation Questionnaire

Respondent	n	CC-TOT	SD	PC-TOT	SD	SI-TOT	SD
Mother only	42	29.67	9.10	38.02	6.60	32.95	5.87
Father/couple	8	27.63[†]	4.33	38.00[†]	4.33	36.13[†]	2.12

[†] P value >0.05 versus mother only answering questionnaire
CC-TOT = Total of Likert Score for Content of Consultation (maximum 45)
PC-TOT = Total of Likert Score for Process of the Consultation (maximum 50)
SI-TOT = Total of Likert Scored in Social Interaction of the Consultation (maximum 45)
(higher Likert scores represent greater satisfaction and positive perception of the consultation)

TABLE 6.Comparison of Mother's and Father's/Couple State-Trait Anxiety Inventory
(STAI) Scores

Respondent	n	STAT_SC	SD	N	TRAI_SC	SD
Mother only	41	47.49	10.20	40	38.50	9.29
Father/couple	8	45.50[†]	11.04	7	32.86[†]	3.52

[†] P value >0.05 versus mother only answering questionnaire
STAT_SC = State Anxiety Score
TRAI_SC = Trait Anxiety Score
(higher anxiety scores represent higher levels of anxiety)

6.2.1 The Antenatal Consultation Questionnaire (ACQ)

The first analysis looked at the first five questions in the Content of the

Consultation to identify the patient's recall of having received the information and their

satisfaction with the amount of information given. It was assumed that if the information

was not received that this would be classified as "not satisfied" with the amount of

information (Table 7). This assumption could be subject to misclassification error. There

may have been respondents who preferred to not hear the information and not being

provided the information in these cases should be correctly classified as "satisfied" with

the amount of information given. These five questions were selected out because at the

end of the questionnaire, the participants were asked to rank order these same information

topics in terms of what they **wanted to hear** about during the consultation and what

information **they remembered** being helpful after the consultation.

TABLE 7. Respondents' Recall of Receiving Information from the Neonatal Specialist during the Antenatal Consultation and the Percentage of Respondents Satisfied with the Amount of Information Given.

Information Given by Specialist During the Consultation	Number of Respondents to Questionnaire	Recalled Being Given Information n	% Satisfied with Information given[¶] (Agree or Strongly Agree)
Given information on survival	50	49	88
Given information on medical problems	50	50	88
Given information on treatment	50	48	86
Given information on risk of disability	50	37	58
Given information on breastfeeding	50	35	56

[¶] If respondent answered NO to receiving the information, response was categorized as Not Satisfied with information given. (Agree or Strongly Agree = % satisfied in 50 cases)

The responses to the questions in each of the domains of the ACQ, Content of the

Consultation, Process of the Consultation and Social Interaction during the Consultation

are described in Tables 8, 9 and 10. Responses of "agree" or "strongly agree" on the

Likert scale were classified as "satisfied with the information". In Table 8, it is evident

that not all the participants received information on every topic identified in the Content

of the Consultation, but those who did receive information were generally satisfied with the amount of information given. In Table 9, all the respondents assessed the Process of the Consultation and indicated their satisfaction with the different elements of how information was given during the consultation. In Table 10, almost all the participants (1 missing data point) assessed the Social Interaction during the Consultation and their agreement or satisfaction with the different indicators of social interaction during the consultation.

TABLE 8. Respondents' Recall of Receiving Information from the Neonatal Specialist during the Antenatal Consultation in the Domain of Content of the Consultation and their Perception of Satisfaction with the Information Given

Information given during the antenatal consultation as recalled by the patient.	Recalled being given information n	% Satisfied with Information[¶] (Agree or Strongly Agree)
Specialist gave me information about medical problems that my baby might have	50	88.0%
Specialist gave me information about treatments my baby might need	48	89.6%
Specialist gave me information about the chances of survival for my baby	49	89.8%
Specialist gave me information about the risk of mental or physical disability for my baby	37	78.4%
Specialist gave me information about breast feeding my premature baby	35	82.3%
Specialist explained the difference between Level III and Level II care	16	81.3%
Specialist gave me information about how long my baby could be in hospital	42	93.1%
Specialist gave me information about when we could visit my baby in NICU	21	85.7%
Specialist gave me information about who could visit my baby in NICU	15	73.3%
I was satisfied with the TOTAL AMOUNT OF INFORMATION given	49**	71.4%

n = 50

[¶] Satisfaction documented only by respondents who recalled receiving the information

** One respondent did not answer this question

TABLE 9. Respondents' Recall of Receiving Information from the Neonatal Specialist during the Antenatal Consultation in the Domain of Process of the Consultation and their Perception of Satisfaction with the Process

The neonatal specialist:	Responded to question n	% Agreement (Agree or Strongly Agree)
Gave me a chance to ask questions	50	100.0%
Answered my questions in words that were easy to understand	50	92.0%
Asked if I understood the information discussed	50	74.0%
Took time to explain information that I did not understand	50	58.0%
Asked if I had questions about information that had not been discussed	50	74.0%
Gave me a chance to talk about my pregnancy	50	58.0%
Gave me a chance to talk about how I was feeling	50	58.0%
Gave me a chance to talk about what I was worried about	50	80.0%
Gave me a chance to talk about my knowledge of premature babies	50	40.0%
Gave me a chance to talk about my baby	50	60.0%

n = 50

TABLE 10. Respondents' Recall of Receiving Information from the Neonatal Specialist during the Antenatal Consultation in the Domain of Social Interaction / Behaviour and their Perception of Satisfaction with the Information Given

The neonatal specialist:	Responded to question n	% Agreement (Agree or Strongly Agree)
Explained his/her role in the care of my baby	50	78.0%
Explained that the NICU Team begins care in the delivery room	50	82.0%
Told me that my baby would be admitted to NICU	50	86.0%
Explained the NICU Team is available at ALL times for attendance at the delivery	50	80.0%
Explained that I was not responsible for my premature labour	49¶	40.8%
Made it easy for me to talk about what I was worried about	50	72.0%
Told me another meeting could be arranged for further questions	50	60.0%
Offered me an NICU tour to help my understanding of baby's care	50	58.0%
I found it easy to talk to the neonatal specialist	50	76.0%

n = 50
¶ One respondent did not answer this question

At the end of the ACQ, respondents were asked to answer two summary questions on a 5-point Likert scale with the anchors strongly disagree and strongly agree and rank order the content of the information provided during the antenatal consultation. The responses to these statements are described below.

RC-1. "The consultation provided information that helped my understanding and knowledge of what could happen to my baby if she/he was born prematurely."

Ninety-two percent of the respondents agreed or strongly agreed with this statement.

RC-2. "The consultation was helpful in relieving some of my worry and anxiety over my baby."

Seventy-eight percent of the respondents agreed or strongly agreed with this statement.

The rank order of the topics that the patients **wanted to hear about** during the consultation and the rank order of the **information they remember** being most helpful after the consultation are presented below.

Rate in order of importance (#1 being the most important) the information **you wanted to hear about** during the antenatal consultation.

1. Information on chances of survival for my baby.

2. Information on medical problems and conditions my baby might have in the NICU.

3. Information on the risk of handicap or disability for my baby.

4. Information on possible treatments that my baby might need in the NICU.

5. Information about breast feeding my baby.

Rate in order of importance (#1 being the most important) the information **you remember** being the most helpful to you after the antenatal consultation.

1. Information about chances of survival for my baby.

2. Information about medical problems and conditions my baby might have in the NICU.

3. Information on possible treatments that my baby might need in the NICU.

4. Information on the risk of handicap or disability for my baby.

5. Information about breast feeding my baby.

6.2.2. Responses to Open-ended Questions about Information Needs. (Appendix C)

The participants were given an opportunity to answer two open-ended questions about the information from the antenatal consultation

Twenty-one respondents provided written comments to the question "Was there other information that was not discussed that would have been helpful to you? If so, what was that information?" Six wanted more information about longer term outcome and risk of disability or handicap. The other answers were related to need for information on caring for the baby, breast feeding, spending time with the baby, visiting the baby, and when the baby could go home.

Eighteen respondents provided written comments to the question "Were there topics discussed that you would have liked more information on? If so, what were those topics?" Four wanted to hear more about risk of disability or handicap, three wanted more information on chances of survival and two wanted more information on breast feeding. The other responses included more information about antenatal steroids, treatment of the baby, impact of the health of the parents on the baby's health, placental problems, risk from radiologic tests, caring for the baby, breastfeeding the baby and more precise figures on risks for each complication that could occur.

Of the 10 respondents who wanted information on disability, 6 had responded "yes" and 4 had responded "no" to having received this information in Content of the Consultation. Eight respondents who did not recall receiving information on disability in Content of the Consultation made no response to the open-ended questions about other information needs.

6.2.3 Results of the Spielberger State-Trait Anxiety Inventory (STAI)

When the questionnaires answered by the mothers alone were analyzed separately

and then compared with the eight questionnaires answered by the father or couples, there

was no difference in the responses to the STAI (Table 6). Therefore, all the

questionnaires were analyzed together (Table 11) as questionnaires answered by the

respondents and compared with the norms for women age 19 to 39 years. These norms

represented a heterogeneous group of working, but not necessarily pregnant women.[55]

TABLE 11. State Anxiety Scores and Trait Anxiety Scores in Patients Admitted in Preterm or Threatened Preterm Labour after the Antenatal Consultation Compared to Norms for Age and Gender.

State and Trait Anxiety	n	Range	Mean	S.D.	Norms for Age & Gender N=210 Mean (SD)
STAT_SC	49	23-74	47.16**[€]	10.28	35.20 (10.61)
TRAI_SC	47	21-54	37.38[†]	9.15	34.79 (9.23)

STAT_SC – State anxiety score
TRAI_SC – Trait anxiety score
**P value <0.01 versus Norms for age and gender - women, age 19-39 years
[†]P value >0.05 versus Norms for age and gender – women, age 19-39 years
[€]P value <0.01 STAT_SC versus TRAI_SC
(higher anxiety scores represent higher levels of anxiety)

The underlying trait-anxiety scores in this group were higher than normal for

women in this age group, 19-39 years, but not significantly so, mean 37.38 versus 34.79,

and the scores were normally distributed (Table 11, Figure 7). The mean score of 37.38

was at the 65th percentile for women in this age group. In contrast, the state-anxiety

scores in this group were much higher than the normal for women in this age group,

mean 47.16 versus 35.20 and the distribution was positively skewed with greater number

of higher scores (Table 11, Figure 7). The mean score of 47.16 was at the 84th percentile

for women in this age group. Under normal, non-stressful situations the state and trait

anxiety scores should be similar. The state anxiety scores for the respondents were significantly higher than the trait anxiety scores for the group.

FIGURE 7. Distribution of State Anxiety Scores and Trait Anxiety Scores in Patients Admitted in Preterm or Threatened Preterm Labour.

STAT_SC = State Anxiety Score

TRAI_SC = Trait Anxiety Score
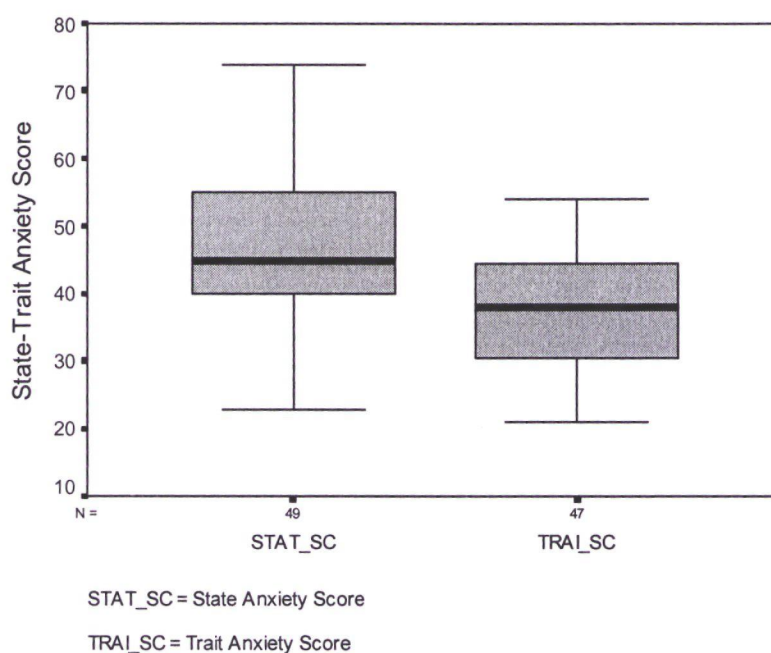
6.2.4 Perception of the Antenatal Consultation and STAI Pre- and Post- Delivery of the Premature Baby

The pre-delivery state anxiety and trait anxiety scores for the subgroup of mothers who delivered premature infants within 7 days of the antenatal consultation were not significantly different from the state and trait anxiety scores for the entire group of respondents, although the numbers in the subgroup are small. The pre- and post-delivery state anxiety and trait anxiety scores were not significantly different from each other. The state anxiety scores for this subgroup of patients, as in the whole group, were significantly different from age and gender norms, whereas the trait anxiety scores were not significantly different from the norms (Table 12).

TABLE 12. Comparison of State and Trait Anxiety Scores in Patients Following Antenatal Consultation, Pre- and Post-delivery of a Premature Infant.

State and Trait Anxiety Score	n	Range	Mean (SD) pre-delivery	n	Range	Mean (SD) post-delivery	Norms for age and gender N=210 Mean (SD)
STAT_SC	$6^\P$	38-74	54.67^{**} (12.69)	7	39-69	$54.86^\dagger$ (10.59)	35.20 (10.61)
TRAI-SC	$6^\P$	29-53	$41.33^\yen$ (10.01)	7	36-54	$43.14^\dagger$ (5.46)	34.79 (9.23)

STAT_SC – State-anxiety score
TRAI_SC –Trait Anxiety score
$\P$ One respondent did not answer all the items in the STAI pre-delivery, but answered all the items post-delivery
** P value <0.01 versus Norms for age and gender – women, age 19-39 years
$\dagger$ P value >0.05 versus pre-delivery score
$\yen$ P value >0.05 (95% CI -1.01, 14.09) versus Norms for age and gender – women, age 19-39 years

After the delivery of their premature baby, all of the seven respondents recalled the antenatal consultation as being helpful in providing them with knowledge and understanding of what might happen with their baby if he/she was born prematurely. Six of these responses did not differ from their responses pre-delivery of the baby, but one moved from being "not sure" to "agree" with the statement after the delivery of the baby. Six of the seven respondents perceived the antenatal consultation as being helpful in reducing their anxiety and worry over their baby and their response to this question was the same in the questionnaire answered pre-delivery. It appears that changing the context of the situation, namely 48 hours after the birth of the premature baby did not change the recalled perception of the antenatal consultation in this small subgroup.

6.3 Principal Component Analysis

The linear relationships among the six variables are provided as a correlation matrix (Table 13). The principal component analyses indicated that the state anxiety

(STAT_SC) and trait anxiety (TRAI_SC) scores were moderately correlated ($r = 0.53$). The anxiety variables were very weakly and non-significantly correlated with the three consultation domains and the Amount of Information ($r = -0.20 - 0.07$). Within the consultation domains, Process of the Consultation and Social Interaction during the Consultation were highly correlated ($r = 0.65$). Content of the Consultation was very highly correlated with the Amount of Information ($r = 0.82$). The inference is that respondents who received more information items, identified as higher scores on Amount of Information, responded with higher Likert scores expressing their agreement with satisfaction with the Content of the Consultation that they recalled.

The domains of the antenatal consultation were related constructs as all these variables mapped to the same quadrant in the principal component analysis (Figure 8). From this analysis it can be concluded that the patient perceptions on the antenatal consultation (e.g., CC-TOT, PC-TOT, and SI-TOT) are poorly correlated to patient anxiety (STAT_SC, TRAI_SC) (i.e., there is no significant relationship between the patient's anxiety and satisfaction with the antenatal consultation). This suggests that the state and trait anxiety scores were not influenced by or related to the antenatal consultation or vice-versa.

TABLE 13. Correlation Matrix for State and Trait Anxiety Score, Amount of Information Items Recalled by the Respondents and the Likert Scores for Content of the Consultation, Process of the Consultation and Social Interaction during the Consultation.

VARIABLE	STAT-SC	TRAI-SC	AMTINFO	CC-TOT	PC-TOT	SI-TOT
STAT_SC	**1.00**	0.53	0.15	0.07	-0.17	-0.17
TRAI_SC	0.53	**1.00**	-0.00	-0.01	-0.20	-0.08
AMT_INFO	0.15	-0.00	**1.00**	0.82	0.29	0.41
CC-TOT	0.07	-0.01	0.82	**1.00**	0.57	0.54
PC-TOT	-0.17	-0.20	0.29	0.57	**1.00**	0.65
SI-TOT	-0.17	-0.08	0.41	0.54	0.65	**1.00**

STAT_SC = State Anxiety Score
TRAI_SC = Trait Anxiety Score
AMT_INFO = Amount of Information (recalled receiving information on 9 items in Content of Consultation)
CC-TOT = Total Likert Score for Content of Consultation
PC-TOT = Total Likert Score for Process of Consultation
SI-TOT = Total Likert Score for Social Interaction during the Consultation

FIGURE 8. Principal Component Analysis of Four Factors from the Antenatal Consultation Questionnaire and Two Factors from the State-Trait Anxiety Inventory

Factor Analysis of Six SubScales
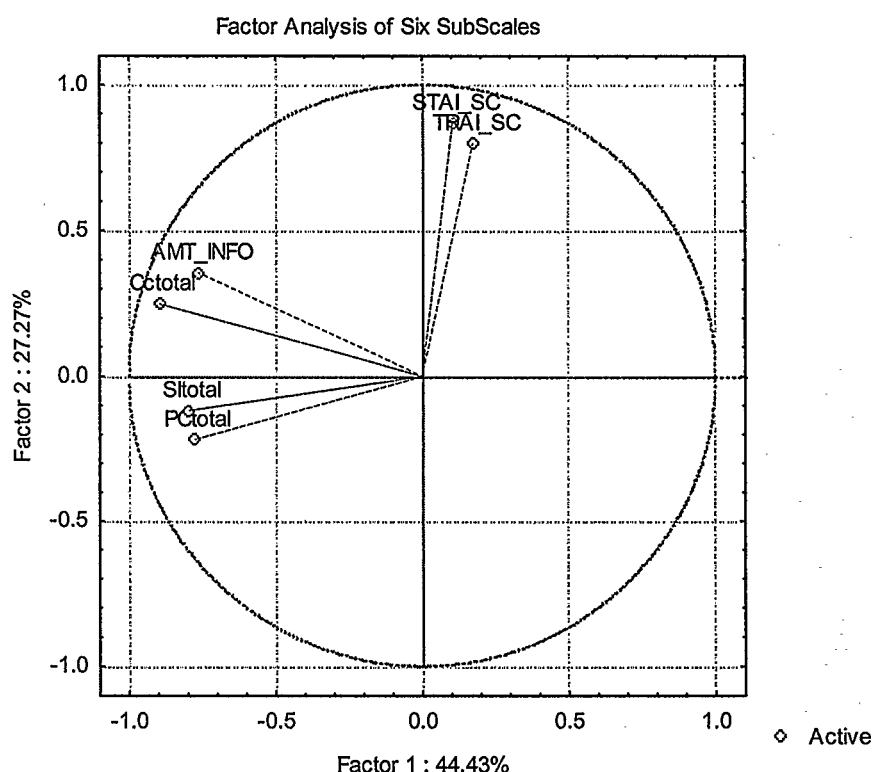
STAI_SC State Anxiety Score
TRAI_SC Trait anxiety Score
CC total Sum of Likert Scores from Content of Consultation
PC total Sum of Likert Scores from Process of Consultation
SI total Sum of Likert Scores from Social Interaction during Consultation
AMT_INFO Number of information items provided during consultation within Content of Consultation (maximum score 9)

The anxiety scales were very weakly correlated with the satisfaction variables from the ACQ so a second correlation matrix (Table 14) was generated using only variables from the ACQ. In this matrix I used as variables the Likert score response to the two summary questions for Rating of the Consultation (RC-1 and RC-2) and the CC-TOT, PC-TOT and SI-TOT from the domains of the consultation. The correlation between the two summary questions RC-1 and RC-2 was 0.61.

TABLE 14. Correlation Matrix for Likert Scores for Rating of Consultation, Content the Consultation, Process of the Consultation and Social Interaction of the Consultation

Variable	RC-1	RC-2	CC-TOT	PC-TOT	SI-TOT
RC-1	1.00	0.61	0.36	0.52	0.50
RC-2	0.61	1.00	0.33	0.43	0.38
CC-TOT	0.36	0.33	1.00	0.51	0.56
PC-TOT	0.52	0.43	0.51	1.00	0.67
SI-TOT	0.50	0.38	0.56	0.67	1.00

RC-1 = Rating of Consultation Question #1 (The consultation provided information that helped my understanding and knowledge of what could happen to my baby if he/she was born prematurely.)
RC-2 = Rating of Consultation Question #2 (The consultation was helpful in relieving some of my worry and anxiety over my baby.)
CC-TOT = Total Likert Score for Content of Consultation
PC-TOT = Total Likert Score for Process of Consultation
SI-TOT = Total Likert Score for Social Interaction during the Consultation

Only one factor or component was extracted from these ACQ variables and the factor loadings for the ACQ variables on this single factor are shown in Table 15. This single factor accounted for 59.4% of the variance in this data. This summary factor represents the sum total of the antenatal consultation as currently delivered in the clinical setting of preterm or threatened preterm labour, providing satisfactory information to the patient. Thus, while five variables from the ACQ were collected, the high interrelationships and the representation of this set of variables on one factor indicated that they all measured a similar construct and should be considered together as important components of the patient's perception of satisfaction with the antenatal consultation.

TABLE 15. Principal Component Analysis and Varimax Normalized Factor Loadings of Five Antenatal Consultation Questionnaire Variables onto One Factor.

VARIABLES in FACTOR 1	FACTOR LOADINGS
RC-1	0.77
RC-2	0.70
CC-TOT	0.72
PC-TOT	0.83
SI-TOT	0.82
Explained Variance (EIGENVALUE)	2.97
Proportion of Total Variance	0.594

RC-1 = Rating of Consultation Question #1
RC-2 = Rating of Consultation Question #2
CC-TOT = Total Likert Score for Content of Consultation
PC-TOT = Total Likert Score for Process of Consultation
SI-TOT = Total Likert Score for Social Interaction of Consultation .

In this analysis, the patients' perception of receiving satisfactory information from the antenatal consultation is the condensed construct derived from 1) having received information that helped the respondents' understanding and knowledge about what could happen to their premature baby, 2) having received information to help relieve worry and anxiety over their baby, 3) satisfaction with the content of the consultation, 4) satisfaction with the process of the consultation and 5) satisfaction with the social interaction during the consultation.

6.4 Relationship Between STAI, ACQ and Sociodemographic Characteristics

The linear relationships between the state and trait anxiety scores and a variable called the Grand Total of the ACQ (the sum of the Likert scores for each of the three domains of the questionnaire) and some select sociodemographic characteristics of the patients admitted with preterm or threatened preterm labour are provided as a correlation matrix (Table 16). It can be seen that the state and trait anxiety scores are significantly correlated ($r = 0.538$) but they have weak correlation ($r = -0.127$ and $r = -0.105$) with the Grand Total score of the ACQ (sum of CC-TOT, PC-TOT and SI-TOT). This confirms

the results obtained through the previous principal component analysis. Anxiety scores were not correlated with any of the sociodemographic characteristics of the study sample. The Grand Total score for the ACQ was positively correlated with the number of pregnancies and the number of miscarriages the respondent had experienced. Mothers of greater gravidity perceived the consultation more favourably. If the pregnancy was the result of assisted reproductive technology this was negatively correlated with this being a singleton pregnancy and negatively correlated with having premature rupture of membranes. Assisted reproductive technology pregnancies in this sample were significantly associated with increase maternal age, multiple gestation, but not premature rupture of membranes.

TABLE 16. Correlation Matrix for State and Trait Anxiety Score, Grand Total Score of Antenatal Consultation Questionnaire and Select Sociodemographic Characteristics of Patients Admitted in Preterm or Threatened Preterm Labour.

	STATE SCORE	TRAIT SCORE	GTOT	Mat Age	#Preg	#Miscar	Singleton	ART	PROM
STAT_SC	1.0	.538**	-.127	-.090	-.084	-.044	.033	-.124	.314
TRAI_SC	.538**	1.0	-.105	-.254	-.023	.019	.042	-.120	.209
G-TOT	-.127	-.105	1.0	-.136	.330*	.398**	-.021	-.100	.104
Mat Age	-.090	-.254	-.136	1.0	-.042	-.049	-.048	.373**	-.077
#Preg	-.084	-.023	.330*	-.042	1.0	.893**	-.105	-.133	.133
#Miscar	-.044	.019	.398**	-.049	.839**	1.0	-.054	.029	.059
Singleton	.033	.042	-.021	-.048	-.105	-.054	1.0	-.393**	.244
ART	-.124	-.120	-.100	.373**	-.133	.029	-.393**	1.0	-.288*
PROM	.314	.209	.104	-.077	.133	.059	.244	-.288*	1.0

** *Correlation is significant at the 0.01 level (2-tailed)*
* *Correlation is significant at the 0.05 level (2-tailed)*

STAT_SC = State anxiety score
TRAI_SC = Trait anxiety score
G-TOT = Grand Total score of Likert scales of Antenatal Consultation Questionnaire
Mat Age = Maternal Age
#Preg = Number of pregnancies including the current one
#Miscar = Number of miscarriages previously
Singleton = Current pregnancy is a singleton
ART = Current pregnancy is result of Assisted Reproductive Technology
PROM = Patient has premature rupture of membranes

7.0 Discussion:

7.1 Key Findings

The primary objective of this study was to determine whether the antenatal consultation satisfied the perceived information needs of the patient in preterm or threatened preterm labour. Almost all of the respondents agreed that the antenatal consultation provided information that helped their understanding and knowledge of what might happen if their baby was born prematurely. The majority of the respondents agreed that the antenatal consultation was helpful in relieving some of their anxiety and worry over their baby.

The most important information that the patients **wanted to hear** about was chances for survival for their premature baby. Following in rank order were information on medical problems the baby might have, risk for disability or handicap for the baby, treatments that the baby might have and lastly information on breast feeding.

The information the patients **remembered being most helpful** after the consultation was chances for survival for the baby. Following in rank order, were information on medical problems the baby might have, treatments the baby might have, risk for disability or handicap for the baby and again lastly information on breast feeding.

The level of anxiety experienced by these women in preterm or threatened preterm labour was significantly higher than norms as measured by the Spielberger State Anxiety score, but the baseline Trait Anxiety score of these patients was not significantly different from a normal population similar in age and gender.

In a very small subgroup, this study was unable to demonstrate any difference in the patient's recalled perception of the antenatal consultation before and after delivery of

their premature baby. Similarly, there was no difference in the high anxiety levels of these patients pre- and post delivery of their premature baby.

7.2 Content of the Consultation

The desire for information about chances of survival and medical problems and conditions that the baby might have were ranked first and second by the patients. This information was almost always given by the consultant during the antenatal consultation. The consultants most consistently provided information on these two topics and possible treatments that the baby might need in the NICU. The desire for information about risk for disability or handicap for the infant was ranked third in order of importance by the respondents, and three quarters of the respondents recalled receiving this information. Amongst those who received information about the risk of disability or handicap, fewer reported being satisfied with the amount of information given compared with satisfaction amongst those who received information on the topics of chances for survival, treatment or medical problems.

This is consistent with Perlman's study[48] of parents interviewed after their baby was admitted to the NICU. The parents recalled information on current management in greatest detail and diagnosis and prognosis was secondary. The parents of critically ill neonates were particularly helped by concrete and specific information about management, rather than information about prognosis and diagnosis perceived to be important by the physicians. Though the consultants were less likely to provide information about the risk of disability, it is unclear if the respondents felt that this information was not as important (ranked third) at the time of the consultation and did not ask about it, or if they did not feel that they could ask for this information if it was not

spontaneously offered in the course of the consultation. In the context of potential preterm labour, chances for survival may intuitively be the first question in the mind of the prospective parents and the risk for disability may seem less important because it appears to be a more remote concern. Similarly, breast feeding may seem to be a remote concept weighted against survival and be perceived to be of lesser importance in this setting of the antenatal consultation.

In contrast, more respondents recalled receiving information about how long they could expect the baby to be in hospital, but fewer recalled receiving information on when they could visit the baby and who could visit the baby in the NICU. From this questionnaire, it cannot be discerned if this information was asked for by the parents or if it was offered spontaneously during the consultation. These results are similar to Paul's[54] findings where 20% of their respondents indicated they were told too little about long-term neurologic disabilities, stresses associated with admission to the nursery and visiting policies.

7.3 Process of the Consultation

Satisfaction with how the information was delivered during the antenatal consultation was generally high. The strengths identified were that the respondents agreed that the neonatal specialist gave them a chance to ask questions, agreed that their questions were answered in words that were easy to understand and agreed that they were given a chance to talk about what they were worried about. The consultants were only moderately successful in allowing for discussion of information that the patient did not understand. It would appear that the consultants did not always ask the patients if they understood the information presented and did not further explain information that the

patients did not understand. The corollary to this situation is that the patients may not have felt empowered to ask the consultant about information that they did not understand or were unwilling to acknowledge their lack of understanding of the information as it was presented to them. Respondents reported that the consultants did not allow much opportunity for patients to talk about their pregnancy, their baby and how they were feeling at this time of threatened preterm labour. It is unclear if this is the result of having to provide a certain volume of information in a limited time or if the consultants were not sensitive to the patients' needs to express themselves and did not encourage them to do so in this setting. Further research is needed to address this question.

7.4 Social Interaction in the Consultation

The neonatal specialist (consultant) always introduced himself/herself, however this did not mean that the patient was able to clearly distinguish the neonatologist from other members of the multidisciplinary team. The patients recognized that the consultant was from the neonatal service dealing with the care of premature babies. The confusion of the general public over the hierarchical and various members of broad multidisciplinary teams in the teaching hospital is common (personal clinical experience).

Most of the patients recalled that the consultant explained their role in the care of the premature baby, the availability of the NICU team and their role in the care of the baby and the expected admission of the baby to the NICU. This was important as the concept of the NICU and separation of the baby from the mother could have been very threatening to the parents. However, it is of concern that some of the patients did not recall this information from the consultation and may not have been clear about what would happen to their baby after he/she was born. Parents have reported that a tour of the

NICU prior to their baby being delivered was helpful as it allowed them to see where their baby would be cared for and what other babies of similar gestation looked like. In this study, less than two thirds of the respondents recalled being offered a tour of the NICU during the antenatal consultation, so either the physicians did not think this was important or they presumed that it would be attended to by others, such as the nursing staff.

The patients were moderately comfortable talking to the neonatal specialist. Most patients recalled that the neonatal specialist made it easier for them to talk about what they were worried about and reported that they found it easy to talk to the neonatal specialist. Less than half of patients recalled the neonatal specialist explaining to them that the patient was not responsible for her premature labour. Brazy et al[49] identified this as a parental concern in their study.

The responses to the open ended questions suggested that more information was desired to address the psychosocial needs of being parents of a baby. The respondents wanted to know about spending time with their baby, holding their baby, visiting their baby and caring for their baby.

7.5 Respondent Anxiety

The high state anxiety scores reported by respondents in this study suggested that they perceived themselves to be in a very stressful situation. The trait anxiety scores suggested that their underlying levels of anxiety were similar to the norms for age and gender. However, from this study alone, it was impossible to discern if this stressful situation was being pregnant or being pregnant and at risk for having a premature infant because of preterm or threatened preterm labour or all of the preceding factors plus being

admitted to hospital. None of the demographic variables or pregnancy-associated conditions were correlated with the state anxiety scores. The norms used for comparison were working females in the same age group, but not necessarily pregnant women. The mean age of the women in this study were comparable to the mean age of women in Zupanic's study,[53] but the mean state anxiety score in this study was higher than the median score of Zupanic's group. The state anxiety scores in this study were positively skewed, so comparison to the median score in Zupanic's study is not valid without knowing the distribution in his data.

In the context of preterm or threatened preterm labour, the study respondents were very anxious as expected. Four-fifths of the respondents agreed that the consultation helped to relieve some of their anxiety and worry over their baby, but the study was not able to quantify the reduction in anxiety. This was only the subjective response of the respondents. The state anxiety scores reported in this study were measured after the antenatal consultation, but not prior to the consultation.

7.6 Principal Component Analysis and Bivariate Analysis

In the principal component analysis, the responses to the antenatal consultation questionnaire were weakly correlated to the responses to the STAI. Therefore, though most of the respondents agreed that the antenatal consultation helped to relieve some of the anxiety and worry over their babies, it would appear that the STAI does not capture the same construct in this group of patients as the question asking for the patient's overall perception of the consultation being helpful in relieving anxiety and worry. In the bivariate analysis there was no or very weak correlation between the STAI scores or the

composite antenatal questionnaire score and sociodemographic factors such as maternal age, the presence of ruptured membranes, pregnancies resulting from assisted reproductive technologies, multiple gestation pregnancies or history of previous miscarriages. The patients' anxiety states reflected the circumstance of being in a very stressful situation. In this homogeneous sample, demographic characteristics contributed little to explaining their level of stress.

7.7 Information, Perception and Anxiety

The discussion of medical problems, conditions and treatments that the premature baby might need in the NICU was almost always provided. This information may have been more easily offered as it represented the day to day activities of the NICU and was much more generic in nature than the more detailed and specific information about risks for longterm disability. The information about chances for survival, medical problems, conditions and treatments that the baby might have was likely new knowledge for the parents. It may be that respondents perceived this information as contributing to their understanding and knowledge about what might happen to their premature baby. However, this study was unable to verify the content of the information provided or the actual information that the parents retained as contributing to their perception of knowledge and understanding about the premature baby. It is possible that respondents reported information obtained from sources other than the antenatal consultation.

The information provided, though detailed and helpful in terms of acquired knowledge, may also have been threatening and worrisome because of its nature and consequences for the baby and the parents. Receiving information may contribute to one's knowledge and understanding of a situation, but it does not necessarily mitigate

against the seriousness or threat of the situation. Therefore, having information may in some circumstances contribute to anxiety and worry as the new information may allow one to consider problems that may not have been apparent to the individual before receiving the information. The information on chances of survival and risk of disability and handicap may have made the antenatal consultation less successful in relieving anxiety and worry about the baby because of the element of uncertainty. The information about possible medical problems and treatments that the baby might need may have been worrisome because of its highly technical nature. In the absence of information, uncertainty is greater but being given an actual risk figure may be equally distressing if it is not a figure you are prepared to hear.

As an example of this possibility, consider the qualitative responses from two of the study respondents. In response to the statement "The antenatal consultation was helpful in relieving some of my worry and anxiety over my baby", one respondent wrote "it made me worry more" and another wrote "actually it freaked me out a bit". The first respondent strongly agreed that the consultation provided information that helped her understanding and knowledge of what could happen to the baby if he/she was born premature and the second respondent answered "agree" to this same statement. In Paul's study,[54] amongst the mothers who delivered infants at less than 30 weeks gestation, 30% of the mothers said they were more worried after the consultation compared to 8% in the group with infants greater than 30 weeks gestation. Similarly, significantly more mothers of the less than 30 weeks gestation infants classified the consultation as stressful and found the consultation less comforting than the mothers of infants of greater gestation.

The literature would suggest that the patients have a need and a right to know all the information "good or bad." However, in the context of high risk patients, the negative nature of some information may confirm patients concerns and lend credence to their worry and anxiety, rather than alleviate it.

The responses to my questionnaire leads one to question if some of Brazy's observations[49] played a role in my study. The respondents in my study had very high anxiety scores, but most of the women were not in active labour as they were seen on the antepartum unit. Some of the respondents did not receive information on certain topics, such as the risk for disability and information on breastfeeding, and it is unclear if they were able to ask for it either. Brazy's study suggests that this may be due to "not knowing what questions to ask, not knowing what was really important and the seeming unreality of the whole situation."

The goal of the antenatal consultation is to provide the parents of potential premature babies with information. However, does the provision of information to patients necessarily result in relieving worry and anxiety in the patients? From this study, it would appear that the two concepts are related, but one does not necessarily follow the other. This may have been because the information provided was negative and not what the patient wanted to hear, or the information contained a lot of uncertainty leading to more worry. Despite this, the respondents generally perceived some relief of their worry and anxiety over their baby. This may be explained by the high and moderately high scores on the second and third domains of the consultation, the Process of the Consultation and the Social Interaction during the Consultation. It is possible that in this current study, the response to the statement that the consultation helped to relieve some of my worry and

anxiety, was a proxy or surrogate for the concept of "help make me feel better" or "feeling emotional support." Wortman[33] suggests that information is important as it serves as a means of support and relates to the perception of emotional support or needs addressed. In Paul's study[54] 71% of the mothers reported being "comforted by the consult."

Gordon's [61] review of the literature suggests that patients do want information, "good or bad" and that even in situations of uncertainty, patients are more satisfied with physician-patient communication if the doctors are able to share information about uncertainty. Therefore, doctors need to remain current with outcomes for their patients and be able to have frank open discussions about uncertainty in prognosis. This approach promotes the concept of mutuality and shared decision-making in physician-patient relationships.

8.0 Implications for Clinical Practice:

The rationale for undertaking this study was that I wanted to know if the antenatal consultation in its current delivery was successful in meeting the perceived information needs of the patients served. I wanted to understand this prior to addressing the issue of risk communication in situations of extreme prematurity requiring decision-making at the margins of viability.

Studies have demonstrated the incongruence between what physicians state they discussed with patients and what patients state was discussed during physician-patient encounters[9,48,53] Yet it is what the patient recalls or their perception of what occurred that affects their satisfaction with the communication encounter.

Koh[62] has suggested providing parents with audiotapes of the consultation so that they could review its content at different times and with other members of their family. This approach is useful if the information provided can be digested remote from the actual consultation, but if the information during the consultation is necessary for the parents to take an active role in decision-making at the time of the consultation, this becomes less feasible. This situation would occur in the context of a mother presenting in preterm labour at a gestation where the fetus is at the margins of viability. Decisions regarding the implementation or the withholding of aggressive intervention are often made during the antenatal consultation, with the risk of imminent delivery being more probable. The women in this study were at lower risk of imminent delivery as most of them were seen on the antepartum ward and not in active labour.

It may be more important to consider the context of the situation when providing information to patients during the antenatal consultation. Women in active labour and/or under the influence of sedation may not be able to hear or comprehend all of the information discussed in the course of the antenatal consultation. Brazy et al[49] stated that "another factor that influenced learning was the parent's own capacity to take in the information. Before and just after birth, the strain of the pregnancy and delivery limited what they could absorb." It may be more appropriate to discuss a limited number of topics in some situations. From the patient responses in this study, the rank order of those topics would be chances for survival, medical problems or conditions the baby might have, risk for disability, treatments the baby might have and breastfeeding. This would suggest a need for a second consultation to provide further information, recognizing that

this could be in the context of post-delivery or following resolution of false labour without delivery.

Another format could be to provide the information through direct physician-patient interaction and provide the patient with written information that they could refer to later with an opportunity to ask for clarification if needed. This could address the concerns raised in Brazy's study[49] about the parents "not knowing what questions to ask, not knowing what was really important and the seeming unreality of the whole situation." In my study, over half of the respondents recalled that the consultant offered opportunity for another meeting to be arranged if they had any further questions. However, if decisions regarding resuscitative intervention need to be made, it may not be possible to delay information giving for the purposes of obtaining parental input for informed consent.

The task of addressing prognosis, manifested as the chances for survival or mortality and the risk of disability or handicap underpins the concept of risk communication. The success of this risk communication should be fundamental to supporting the idea of informed consent. If parents are to be enabled to fully participate in the process of informed consent, there must be assurances that physicians are able to communicate risks about their children (born or unborn) to the parents.

Part of the dilemma lies in the uncertainty of outcomes for the extremely premature infant as reports of outcomes range widely from centre to centre and the interpretation of these results among disciplines involved in the provision of perinatal-neonatal care.[63,64,65,66,67] These same studies show good to very good outcomes for premature infants of greater gestational age. Physicians need to be comfortable with the outcomes of these premature infants for the parents who are seeking information and guidance during

the antenatal consultation. This dilemma becomes more complex when dealing with the extremely premature infant, as the experiences of any individual centre may be limited by the actual numbers of patients available to provide long term follow-up information. The discrepancy in the estimation of outcomes of these infants by the different disciplines[63,64] underlies the need for the neonatologists to be aware of their local experience and to be able to communicate the messages to the patients without disparity in interpretation. In this study, I limited the gestational age to premature infants beyond 24 weeks gestation, (there were two 24 week gestation respondents in this study) for which there is good data for longterm outcome, with the expectation that physicians would be able to provide this information to the parents during the antenatal consultation.

This study suggests that the antenatal consultation, as it is currently delivered, provides information that is perceived to be helpful by the patients. However, there is room for improvement to be made in the area of risk communication during the antenatal consultation as it pertains to the longterm outcome for the premature infant. By improving the skills of physicians in this aspect of communication, the patient may be allowed to enter into an informed shared decision-making relationship with the physician to direct the care of the premature infant. This goal is desirable when contemplating the direction of management for fetuses that are at borderline viability or for ongoing care in the NICU when other critical decisions concerning care will arise.

Physicians also need to be more sensitive to the concept that patients need to talk during the antenatal consultation, to express their concerns and ask about information that they do not understand in the course of the consultation. Patients would like physicians to

address more psychosocial issues relating to the parents' care and interaction with their premature baby.

9.0 Strengths and Limitations:

The strengths of this study was that there was a good response rate to the questionnaire, recognizing that some of the initial questionnaires were given to women in active labour without enough opportunity to complete the questionnaire before delivery. The study sample was reflective of the population of women in Calgary, Alberta characterized by higher maternal age, well educated and with good income levels. The Cronbach's alpha for the new ACQ developed specifically for this study were acceptable, demonstrating good internal consistency of the items within the domains.

In this study I tried to capture the perceived information needs of women who were potentially going to deliver a premature baby before their information needs were confounded by prolonged exposure to the hospital and NICU environment. In Paul's study[54] the mothers were asked about their recalled perception of the antenatal consultation just prior to discharge home from the NICU after a mean stay of 40 days. I deliberately excluded women whose pregnancies were at a gestation of borderline viability to avoid the complex information and decision making that is inherent in antenatal consultations done at those early gestations. I was interested in the delivery and the perception of the information provided and not necessarily the process of decision making in this study.

This study has several limitations. The study was not designed to assess or quantify the increase in knowledge of the study respondents following the information given during the antenatal consultation. It only addressed the study respondent's perception of

having been provided with information that helped their understanding and knowledge about premature babies from the antenatal consultation. Similarly, the study was not designed to verify the content of the information that was given to the patients during the antenatal consultation, but was based on the study respondents' recall of information content that was provided. The study could not assess the quality of the physician social interaction and delivery of information, but a significant proportion of the respondents indicated a need for opportunity to talk about their feelings, their pregnancy and their baby. The state anxiety scores were compared to norms for a population similar in age and gender, but comparisons could not be made with a standard, low risk group of similar aged pregnant women.

In this study, the respondent's anxiety level prior to the antenatal consultation was not assessed. The respondents indicated their anxiety in the responses to the STAI, which was administered after the antenatal consultation. It was not possible to quantify if there was a change in the level of anxiety after the consultation. I only have the respondents' overall perception of their relief of worry or anxiety after the antenatal consultation. This perception did not appear to match the construct of anxiety as measured by the STAI. It would seem that having received information was not sufficient to relieve the high degree of anxiety experienced by these patients. In fact, it is possible that information given during the course of the antenatal consultation may have exacerbated the anxiety and stress experienced by the parent in this setting. This requires further exploration. The overall satisfaction with the antenatal consultation was high and it was not possible to identify what factors led to dissatisfaction for the prospective parents of premature babies.

This study did not look at the possible different information needs of mothers compared to fathers. The study respondents were too homogeneous a group to be able to discern factors that would identify differential information needs of different groups of patients. A convenience sample of English-speaking patients from the antepartum unit, not in active labour limits the generalizability of the study results. It did not give insight into the information needs of women in active labour at threat of imminent delivery of a premature baby or women who may deliver infants at the lower extremes of viability.

10.0 Future Studies:

The information needs of patients dependent upon the context of the situation deserves further attention. The information needs of mother's in active preterm labour with imminent delivery may be limited by their capacity to absorb large amounts of information and information giving may need to be tailored to these needs. This group was not captured in this study. Similarly, the information needs of parents may depend on the gestational age of the potential premature infant, as lower gestational age represents higher risk. The small sample size in this study was unable to differentiate these needs. The information needs of patients at threat of delivering premature babies at the extremes of viability, less than 24 weeks gestation, need to be addressed. Information provided to these patients will impact the decision-making process in these situations. The presentation of risk information needs to be explored as there are conflicting studies as to patient preferences for risk information given in numeric versus in qualitative terms. Positive versus negative framing of risk information may also impact patient perception and understanding in this situation. This study did not verify how risk information was delivered during the consultation. An understanding of these factors may further advance

the process of the antenatal consultation and allow for more optimal informed consent of parents of potentially premature infants. The development of an information sheet to be used as an adjunct to the antenatal consultation should be considered and evaluated. A template for a structured antenatal consultation could eventually be developed as an educational tool.

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Appendix A

Does the Antenatal Consultation Meet the Perceived Information Needs of the Patient in Preterm or Threatened Preterm Labour?

STUDY QUESTIONNAIRE # _____

Name _____

Date of Birth _____

This information will be used to match the questionnaires that you have been asked to complete now and after your baby is born. Once the questionnaires have been matched, your name and date of birth information will be removed and only the study questionnaire number (#) will be kept. When you have completed the questionnaire, please place it in the addressed envelope provided and return it to your nurse. Thank you for taking the time to fill out this questionnaire.

**Please note that Part 2 of the questionnaire (in Blue print) has two sides and we would like you to answer the questions on both sides of the sheet. Thank you.

Research Project Title: **Does the Antenatal Consultation Meet the Perceived Information Needs of the Patient in Preterm or Threatened Preterm Labour?**

Investigators: **Wendy Yee M.D, Reg Sauve M.D.**

INTRODUCTION TO THE ANTENATAL CONSULTATION STUDY QUESTIONNAIRE

You were admitted to the hospital with premature labour. Because your baby might be born early you met with a Neonatal Specialist from the Neonatal Intensive Care Unit (NICU). A Neonatologist is a doctor ("baby doctor") who specializes in the care of sick and premature babies who are admitted to the NICU. A Neonatal Fellow is a doctor who is learning to specialize in the care of sick and premature babies and works directly under the neonatologist. We call this meeting with the neonatal specialist a consultation. In your situation, this meeting occurred before the birth of your baby so it is called the antenatal (before birth) consultation. At the meeting with the neonatal specialist you received information about how your baby might be cared for if he/she was born early.

The purpose of this study is to ask you some questions about the information you received from the antenatal consultation. From this study, we would like to learn how to provide the most important and most helpful information to other women in a similar situation. How helpful was the discussion with the neonatal specialist? Was there other information that you would have liked to talk about?

There are three parts to this questionnaire. The first part is about the information that you received during the consultation with the neonatal specialist from the NICU. The second part asks you about how you are generally feeling now that you are in hospital. The last part asks about you.

Please answer all of the questions. All information will be kept confidential and your name will not be identified in any reports about the study.

Antenatal Consultation Study Questionnaire – Part 1

I had a consultation with the following neonatal specialist (Please check one)
    Neonatologist
    Neonatal Fellow
    Other (Neonatal Nurse Practitioner, Pediatrician): Please specify_____
    Not Sure

During the consultation my husband/partner was in the room. Yes   No
Other person(s) in the room: Please specify _____

The person answering this questionnaire is the: Mother   Father

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In the following series, please answer Yes/No questions by checking Yes or No, and then circle the response that matches your level of agreement with each of the statements.

1=Strongly Disagree   2=Disagree   3=Not Sure   4=Agree   5=Strongly Agree

CONTENT OF CONSULTATION

1. The neonatal specialist gave me information about medical problems and conditions that my baby might have. (breathing problems, infection, bleeding on the brain, feeding problems or premature eye problems)   Yes   No
If yes, I was satisfied with the amount of information given.

1=Strongly Disagree   2=Disagree   3=Not Sure   4=Agree   5=Strongly Agree

2. The neonatal specialist gave me information about treatments that my baby might need. (breathing machines, intravenous therapy, surfactant, drugs or surgery)   Yes   No
If yes, I was satisfied with the amount of information given.

1=Strongly Disagree   2=Disagree   3=Not Sure   4=Agree   5=Strongly Agree

3. The neonatal specialist gave me information about the chances of survival for my baby.   Yes   No
If yes, I was satisfied with the amount of information given.

1=Strongly Disagree   2=Disagree   3=Not Sure   4=Agree   5=Strongly Agree

4. The neonatal specialist gave me information about the risk for possible mental and physical disability (handicap) for my baby.   Yes   No
If yes, I was satisfied with the amount of information given.

1=Strongly Disagree   2=Disagree   3=Not Sure   4=Agree   5=Strongly Agree

5. The neonatal specialist gave me information about breast feeding my premature baby.   Yes   No
If yes, I was satisfied with the amount of information given.

1=Strongly Disagree   2=Disagree   3=Not Sure   4=Agree   5=Strongly Agree

6. The neonatal specialist explained the difference between the Level III (NICU) and the Level II (Special Care Nursery)?   Yes   No
If yes, I was satisfied with the amount of information given.

1=Strongly Disagree   2=Disagree   3=Not Sure   4=Agree   5=Strongly Agree

7. The neonatal specialist gave me information about how long my baby could be in the hospital.   Yes   No
If yes, I was satisfied with the amount of information given.

1=Strongly Disagree   2=Disagree   3=Not Sure   4=Agree   5=Strongly Agree

8. The neonatal specialist gave me information about when we could visit my baby in the NICU.   Yes   No
If yes, I was satisfied with the amount of information given.

1=Strongly Disagree   2=Disagree   3=Not Sure   4=Agree   5=Strongly Agree

9. The neonatal specialist gave me information about who could visit my baby in the NICU.   Yes   No
If yes, I was satisfied with the amount of information given.

1=Strongly Disagree   2=Disagree   3=Not Sure   4=Agree   5=Strongly Agree

10. I was satisfied with the **total amount of information** given during the consultation.

1=Strongly Disagree   2=Disagree   3=Not Sure   4=Agree   5=Strongly Agree

PROCESS OF CONSULTATION

1. The neonatal specialist gave me a chance to ask questions.

1=Strongly Disagree   2=Disagree   3=Not Sure   4=Agree   5=Strongly Agree

2. The neonatal specialist answered my questions in words that were easy to understand.

1=Strongly Disagree   2=Disagree   3=Not Sure   4=Agree   5=Strongly Agree

3. The neonatal specialist asked if I understood the information being discussed.

1=Strongly Disagree   2=Disagree   3=Not Sure   4=Agree   5=Strongly Agree

4. The neonatal specialist took time to explain information that I did not understand.

1=Strongly Disagree   2=Disagree   3=Not Sure   4=Agree   5=Strongly Agree

5. The neonatal specialist asked if I had questions about things that had not been discussed.

1=Strongly Disagree   2=Disagree   3=Not Sure   4=Agree   5=Strongly Agree

6. The neonatal specialist gave me a chance to talk about my pregnancy.

1=Strongly Disagree   2=Disagree   3=Not Sure   4=Agree   5=Strongly Agree

7. The neonatal specialist gave me a chance to talk about how I was feeling.

1=Strongly Disagree   2=Disagree   3=Not Sure   4=Agree   5=Strongly Agree

8. The neonatal specialist gave me a chance to talk about what I was worried about.

1=Strongly Disagree   2=Disagree   3=Not Sure   4=Agree   5=Strongly Agree

9. The neonatal specialist gave me a chance to talk about what I knew about premature babies.

1=Strongly Disagree   2=Disagree   3=Not Sure   4=Agree   5=Strongly Agree

10. The neonatal specialist gave me a chance to talk about my baby.

1=Strongly Disagree   2=Disagree   3=Not Sure   4=Agree   5=Strongly Agree

SOCIAL INTERACTION/BEHAVIOUR

1. The neonatal specialist introduced himself/herself.   Yes   No

2. The neonatal specialist explained what his/her role would be in the care of my baby.
1=Strongly Disagree   2=Disagree   3=Not Sure   4=Agree   5=Strongly Agree

3. The neonatal specialist explained that the Neonatal Intensive Care team would come at the time of delivery and start looking after my baby in the delivery room.
1=Strongly Disagree 2=Disagree   3=Not Sure   4=Agree   5=Strongly Agree

4. The neonatal specialist told me that my baby would be admitted to the Neonatal Intensive Care Unit (NICU).
1=Strongly Disagree   2=Disagree   3=Not Sure   4=Agree   5=Strongly Agree

5. The neonatal specialist explained that members of the NICU team were available at all times, no matter when I delivered.
1=Strongly Disagree   2=Disagree   3=Not Sure   4=Agree   5=Strongly Agree

6. The neonatal specialist explained that I was not responsible for going into premature labour.
1=Strongly Disagree   2=Disagree   3=Not Sure   4=Agree   5=Strongly Agree

7. The neonatal specialist made it easy for me to talk about what I was worried about.
1=Strongly Disagree   2=Disagree   3=Not Sure   4=Agree   5=Strongly Agree

8. The neonatal specialist told me that another meeting could be arranged if I had any more questions.
1=Strongly Disagree   2=Disagree   3=Not Sure   4=Agree   5=Strongly Agree

9. The neonatal specialist offered me a tour of the NICU to try and make it easier for me to understand where my baby would be looked after.
1=Strongly Disagree   2=Disagree   3=Not Sure   4=Agree   5=Strongly Agree

10. I was found it easy to talk to the neonatal specialist.
1=Strongly Disagree   2=Disagree   3=Not Sure   4=Agree   5=Strongly Agree

RATING OF CONSULTATION

1. The consultation provided information that helped my understanding and knowledge of what could happen to my baby if he/she was born prematurely.

1=Strongly Disagree   2=Disagree   3=Not Sure   4=Agree   5=Strongly Agree

2. The consultation was helpful in relieving some of my worry and anxiety over my baby.

1=Strongly Disagree 2=Disagree 3=Not Sure 4=Agree 5=Strongly Agree

3. Please rate 1-5, in order of importance (#1 being most important) **the information you wanted to hear about** during the antenatal consultation.
   ____ possible medical problems and conditions that my baby might have in the NICU
   ____ possible treatments that my baby might need in the NICU
   ____ the chances of survival for my baby
   ____ the risk for possible mental and physical disability (handicap) for my baby
   ____ breast feeding my premature baby

4. Please rate 1-5, in order of importance (#1 being most important) **the information you remember being most helpful to you** after the antenatal consultation. (N/D if Not Discussed)
   ____ possible medical problems and conditions that my baby might have in the NICU
   ____ possible treatments that my baby might need in the NICU
   ____ the chances of survival for my baby
   ____ the risk for possible mental and physical disability (handicap) for my baby
   ____ breast feeding my premature baby

5. Was there other important information that was not discussed that would have been helpful to you? If so, what was that information? (Please write on the other side if necessary)

_____
_____
_____

6. Were there topics/things discussed that you would have liked more information on? If so, what were those topics? (Please write on other side if necessary)

_____
_____
_____
_____

SELF-EVALUATION QUESTIONNAIRE

Developed by Charles D. Spielberger
in collaboration with
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STAI Form Y-1

Name _____ Date _____ S _____

Age _____ Sex: M _____ F _____   T _____

DIRECTIONS: A number of statements which people have used to describe themselves are given below. Read each statement and then blacken in the appropriate circle to the right of the statement to indicate how you feel *right* now, that is, *at this moment*. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feelings best.

	NOT AT ALL	SOMEWHAT	MODERATELY SO	VERY MUCH SO
1. I feel calm	①	②	③	④
2. I feel secure	①	②	③	④
3. I am tense	①	②	③	④
4. I feel strained	①	②	③	④
5. I feel at ease	①	②	③	④
6. I feel upset	①	②	③	④
7. I am presently worrying over possible misfortunes	①	②	③	④
8. I feel satisfied	①	②	③	④
9. I feel frightened	①	②	③	④
10. I feel comfortable	①	②	③	④
11. I feel self-confident	①	②	③	④
12. I feel nervous	①	②	③	④
13. I am jittery	①	②	③	④
14. I feel indecisive	①	②	③	④
15. I am relaxed	①	②	③	④
16. I feel content	①	②	③	④
17. I am worried	①	②	③	④
18. I feel confused	①	②	③	④
19. I feel steady	①	②	③	④
20. I feel pleasant	①	②	③	④

SAMPLE

SELF-EVALUATION QUESTIONNAIRE
STAI Form Y-2

Name _____ Date _____

DIRECTIONS: A number of statements which people have used to describe themselves are given below. Read each statement and then blacken in the appropriate circle to the right of the statement to indicate how you *generally* feel. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe how you generally feel.

	ALMOST NEVER	SOMETIMES	OFTEN	ALMOST ALWAYS
21. I feel pleasant	①	②	③	④
22. I feel nervous and restless	①	②	③	④
23. I feel satisfied with myself	①	②	③	④
24. I wish I could be as happy as others seem to be	①	②	③	④
25. I feel like a failure	①	②	③	④
26. I feel rested	①	②	③	④
27. I am "calm, cool, and collected"	①	②	③	④
28. I feel that difficulties are piling up so that I cannot overcome them	①	②	③	④
29. I worry too much over something that really doesn't matter	①	②	③	④
30. I am happy	①	②	③	④
31. I have disturbing thoughts	①	②	③	④
32. I lack self-confidence	①	②	③	④
33. I feel secure	①	②	③	④
34. I make decisions easily	①	②	③	④
35. I feel inadequate	①	②	③	④
36. I am content	①	②	③	④
37. Some unimportant thought runs through my mind and bothers me	①	②	③	④
38. I take disappointments so keenly that I can't put them out of my mind	①	②	③	④
39. I am a steady person	①	②	③	④
40. I get in a state of tension or turmoil as I think over my recent concerns and interests	①	②	③	④

SAMPLE

Antenatal Consultation Study Questionnaire – Part 3

INFORMATION ABOUT YOU

Please answer the following questions about yourself. Answer Yes/No questions by checking either Yes or No. If a blank is provided, please fill in the blank with your answer.

1. Number of pregnancies you have had including the current one _____
2. Number of previous children born alive _____
3. Number of previous miscarriages _____
4. Number of previous abortions _____
5. Current pregnancy is a singleton (one baby)   Yes   No
6. Current pregnancy is a multiple gestation   Yes   No
   If yes, please circle one of the following: twins, triplets, quadruplets, other.
7. Was this pregnancy medically assisted, (fertility drugs, Clomid, in-vitro fertilization)?
   Yes   No
8. Gestational age. How many weeks along is your pregnancy? _____ weeks
9. Have your membranes ruptured (water broken)?   Yes   No
10. Have you been told you have cervical changes?   Yes   No
11. Are you having contractions now?   Yes   No
12. Please check √ if you have any of the following medical problems:
    high blood pressure   high blood pressure in pregnancy only
    diabetes   diabetes in pregnancy only
    lupus
    thyroid problems
    heart condition
    kidney failure
    depression
    seizures
    other. Please describe.

    _____

    _____

13. Have you ever had a previous stillbirth after 20 weeks gestation?   Yes   No
14. Have you ever had a previous premature baby, born at 36 weeks or less?
    Yes   No
15. Has any abnormality been seen in your baby on ultrasound examination during this pregnancy?   Yes   No
16. Your age _____ years
17. My marital status is best described as, I am (Please check one of the following)
    Single
    Married
    Common-law
    Other

18. My education level is best described as (Please check one of the following)
> Did not complete high school
> Completed high school
> Some College/University
> Completed College/University

19. English is my first language.   Yes   No
20. Socioeconomic status. My **total household income** level is (Please check one of the following)
> less than $40,000 per year
> $41,000 to $80,000 per year
> $81,000 to $120,000 per year
> greater than $120,000 per year

21. I have some previous knowledge of premature babies.   Yes   No
22. My information about premature babies comes from (Please check as many as apply to you)
23.
> my previous premature baby
> family
> friends
> work experience
> newspapers and magazines
> television
> the Internet
> other: Please specify _____

Thank you for answering this questionnaire and contributing to our understanding of the information needs of women in premature or threatened premature labour. Your information will be kept confidential. If you have any questions about any part of this questionnaire please call Dr. Wendy Yee at 943-3424 or 212-8223 (pager 4052).

Appendix B

Does the Antenatal Consultation Meet the Perceived Information Needs of the Patient in Preterm or Threatened Preterm Labour?

STUDY QUESTIONNAIRE # _____

Name _____

Date of Birth _____

This brief questionnaire is a follow-up to the questionnaire that you completed a few days ago. It asks you some of the same questions as the first questionnaire now that your baby is born and in the NICU.

This above information will be used to match the questionnaire that you previously completed and this shorter questionnaire. Once the questionnaires have been matched, your name and date of birth information will be removed and only the study questionnaire number (#) will be kept. When you have completed the questionnaire, please place it in the addressed envelope provided and return it to your nurse. Thank you for taking the time to fill out this questionnaire.

**Please note that Part 2 of the questionnaire (in Blue print) has two sides and we would like you to answer the questions on both sides of the sheet. Thank you.

RATING OF CONSULTATION

1. The consultation provided information that helped my understanding and knowledge of what could happen to my baby if he/she was born prematurely.

1=Strongly Disagree   2=Disagree   3=Not Sure   4=Agree   5=Strongly Agree

2. The consultation was helpful in relieving some of my worry and anxiety over my baby.

1=Strongly Disagree   2=Disagree   3=Not Sure   4=Agree   5=Strongly Agree

3. Please rate 1-5, in order of importance (#1 being most important) **the information you wanted to hear about** during the antenatal consultation.
   ____ possible medical problems and conditions that my baby might have in the NICU
   ____ possible treatments that my baby might need in the NICU
   ____ the chances of survival for my baby
   ____ the risk for possible mental and physical disability (handicap) for my baby
   ____ breast feeding my premature baby

4. Please rate 1-5, in order of importance (#1 being most important) **the information you remember being most helpful to you** after the antenatal consultation. (N/D if Not Discussed)
   ____ possible medical problems and conditions that my baby might have in the NICU
   ____ possible treatments that my baby might need in the NICU
   ____ the chances of survival for my baby
   ____ the risk for possible mental and physical disability (handicap) for my baby
   ____ breast feeding my premature baby

5. Was there other important information that was not discussed that would have been helpful to you? If so, what was that information? (Please write on the other side if necessary)

_____
_____
_____
_____

6. Were there topics/things discussed that you would have liked more information on? If so, what were those topics? (Please write on other side if necessary)

_____
_____
_____
_____

Appendix C
Responses to Open-ended Questions.

<u>**Responses to RC-5**</u>
Was there other important information that was not discussed that would have been helpful to you? If so, what was that information?

- Not sure, too early for questions
- Treatments of possible problems which arise from premature birth. Reassurance of having a healthy baby at 27 weeks
- Just a little more information on breastfeeding, like how often do I need to come in.
- Process at and after birth wasn't clear. Mental and psychological development issues. Tour would have been helpful. Discussion on bottle feeding premies.
- Visiting information for NICU.
- Yes, what are the chances of my baby coming out handicap.
- Would I be able to spend time with my baby.
- Health of the baby such as medical problems, survival and physical disability are very, very important to us.
- We would like more info on when we would be able to visit our babies as well as who else.
- I wouldn't know as this is all very new to me.
- No, felt that information was helpful and combined with the tour by nurse, we had all our questions answered.
- What would happen at the actual time of birth – would I be able to hold by baby – would he cry?
- Mental disability, seeing the ICU, when I could see my baby.
- It is nice to hear of stories of people and/or cases of success and failure stories pertinent to your gestation not just statistics and probabilities. Getting to see another premature baby up close and/or being introduced to families or prems in the NICU.
- Due to language difficulty the antenatal was hard to understand.
- I would have liked to know the criteria to be met by the babies before they could go home.
- Maybe more information on how the parents can care for the baby and anything that can make it easier for the baby.
- More information on who could visit the baby.
- Physical and mental disabilities were not discussed in depth.
- No, my situation is up in the air somewhat as I do not know the extent of my baby's heart problem, although many different scenarios were explained to me.
- Can you still breast feed premature babies? How long do premies need to be in hospital after they are born? Can they develop serious problems a few months after birth resulting from premature delivery? Who will be able to see my baby while he's in the NICU?

Responses to RC-6

Were there topics/things discussed that you would have liked more information on? If so, what were those topics?

- Yes, everything.
- Chances for survival for my baby. Possible problems and conditions.
- More on breastfeeding.
- Mental and physical disability.
- The steroids and delivery medicine that were given to me. The side effect of them if there are any.
- More on the treatment of my baby in the NICU. More on difference of development of baby. ie 31 wks vs 35 wks
- Again as in question 5, combined with NICU tour, I felt that we received plenty of helpful information. I think it is wonderful to have had this opportunity to hear about issues/topics related to premature delivery before the actual delivery day. Also, the opportunity to tour the NICU was fantastic and has helped us prepare for what is to come. * After the consultation and NICU tour I am very glad that the opportunity was available and glad that I participated/was given the information but feel some anxiety/fear about having premature babies and concern for their well-being and having to be in special care. But, the information given and tour in a sense has also been very reassuring and I am glad and thankful that it was available. Thank you!!
- Possible disabilities, likelihood of them occurring. First signs that something may be wrong.
- Mental disability, breastfeeding, the ICU.
- It is nice to have statistics and/or probabilities based more on your certain situation directly related to a fact or characteristic specific to your baby and you that relates to the statistics. e.g. baby born to strong healthy parents do better or 1-2 oz weight above the average or your baby can play an important part for your baby.
- Can the placenta move out from the wall could it be dangerous. Would like more information
- I would have liked to know how much of a risk he had of not survival. And how much of possible of mental and physical disability to my baby there is and want.
- Maybe more information on how the parents can care for the baby and anything that can make it easier for the baby.
- Mental disabilities.
- Yes, I am concerned how the many radiological tests I am require to have will affect the fetus (baby).
- A little bit more information on percent of survival rate.
- Breastfeeding my premature baby.
- I would have liked more precise figures in regards to percentages or likelihood of each complication that can occur.

Appendix D.

CONSENT FORM

Research Project Title: **Does the Antenatal Consultation Meet the Perceived Information Needs of the Patient in Preterm or Threatened Preterm Labour?**

Investigators: **Wendy Yee M.D, Reg Sauve M.D.**

This consent form, a copy of which has been given to you, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

You were admitted to the hospital with premature labour. Because your baby might be born early you met with a neonatologist. A neonatologist is a doctor who specializes in the care of sick and premature babies who are admitted to the Neonatal Intensive Care Unit (NICU). A neonatal fellow is a doctor who is training in the care of sick and premature babies and works directly under the neonatologist. We call this meeting with the neonatologist a consultation. In your situation, this meeting occurred before the birth of your baby so it is called the antenatal (before birth) consultation. At the meeting with the neonatologist you received information about how your baby might be cared for if he/she was born early.

The purpose of this study is to ask you some questions about the information you received from the antenatal consultation, how helpful you found the discussion with the neonatologist and whether or not there was other information that you would have liked to talk about. From this study, we would like to learn how to provide the most important and most helpful information to other women in a similar situation.

The study requires you to answer a questionnaire now and again at two days (48 hours) after the birth of your baby if you deliver within 7 days of being admitted to hospital.

If you consent to participate in the study, you will be given a questionnaire to answer. There are three parts to this questionnaire. The first part is a series of questions about the information that you received during the consultation with the neonatologist, how the information was given to you by the neonatologist and how at ease you were with the neonatolgist during the consultation. The second part asks about how you are generally feeling now that you are in hospital. The last part asks about you. If you are

_____   _____
Date   Participant's Initials

unable to answer all the medical questions about yourself, we ask for permission for the investigator to review your current hospital chart to help answer these questions. You will be given the same questionnaire to answer again two days after the birth of your baby.

There is no direct benefit to you from this study. However, we hope to use this information to learn how to provide the most important and most helpful information to other women in a similar situation. We would make this information available to health care providers involved in antenatal care. If you choose not to participate, this will in no way affect the care provided to you or your baby.

The information will be kept confidential and your name will not be identified in any reports from the study, once the two questionnaires have been completed and the information has been entered into a data base. Data base information will be treated confidentially and accessible only to the investigators of this study for the purposes of analysis and preparing written reports of the information.

In the event that you suffer injury as a result of participating in this research, no compensation will be provided for you by the University of Calgary or the Calgary Health Region. You still have all your legal rights Nothing said here about treatment or compensation in any way alters your right to recover damages.

Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate as a subject. In no way does this waive your legal rights or release the investigators, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time without jeopardizing your health care. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation. If you have further questions concerning matters related to this research, please contact: Wendy Yee 943-3424.

If you have any questions concerning your rights as a possible participant in this research, please contact Pat Evans, Associate Director, Internal Awards, Research Services, University of Calgary, at 220-3782.

_____   _____

Participant's Signature   Date

_____   _____

Investigator and/or Delegate's Signature   Date

_____   _____

Witness' Signature   Date