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**PARENTS' DECISION MAKING NEEDS  
REGARDING CIRCUMCISION OF MALE NEWBORNS**

**by**

**Susan Taylor-Clapp**

**Thesis submitted to the  
School of Graduate Studies and Research  
in partial fulfilment of the requirements for the  
degree of Master's of Science in Nursing**

**University of Ottawa**

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## Abstract

This study, conducted as a needs assessment, was guided by O'Connor's Decision Support Framework (DSF). The DSF describes a process of providing to both parents and practitioners decision support by identifying the sub-optimal determinants of the decision. The objectives of the study were to describe the decision making needs of parents making choices about neonatal male circumcision and the needs of prenatal instructors who inform parents about options. The study design was a cross-sectional survey of 88 mothers and 67 fathers and 10 prenatal instructors. Structured questionnaires were used, eliciting variables based on the DSF, such as: the perception of the decision; perception of others regarding the decision; resources to make the decision; and participant characteristics.

Most parents in this study (74%) were college educated with 91% expecting their first child. Three quarters of the study fathers were circumcised. Seventy-four percent of the fathers and 60% the mothers favoured circumcision. The parents' total mean scores (fathers=2.35 out of 5; mothers=2.43 out of 5) for the Decisional Conflict Scale (DCS) revealed mild decisional conflict. Decisional conflict was higher for parents in the early stages of decision making and among the unsure. Factors contributing to decisional conflict included: inadequate information (63%); unclear values (63%); and inadequate support (59%). The average knowledge scores for fathers ( $\underline{M}$ =64.5 out of 100) and mothers ( $\underline{M}$ =60.9 out of 100) were low and the greatest knowledge deficits concerned foreskin anatomy and physiology. Parents were unsure about the expectations of the benefits and harms of options. There was a tendency to overestimate the benefits and underestimate the risks. The most important value affecting parents' decision for circumcision was reducing the risk of infection ( $\underline{M}$ =7.7 out 10) while penile injury ( $\underline{M}$ =8.0 out

of 10) was the most important value against circumcision. Few parents placed any relevance on religious beliefs or cost as a factor in their decision making. The majority of parents shared the decision making with their partner and most relied on information from others' experience with the physician in an advisory role.

Although all instructors stated that circumcision was discussed, the content of the discussion varied according to the instructor's experience and perception of the decision. Most instructors (9/10) believed parents lacked both information about options and chances of the benefits and risks. Few of the instructors (2/10) saw their role as instrumental in the decision. Collectively, the factors that impacted negatively on decision support provided by instructors were related to inadequate teaching experience; time constraints; lack of medical consensus in the literature; frustration with the topic; and personal bias.

This study demonstrated that both parents and instructors have unmet needs related to either making or supporting decisions about circumcision. Decision support for both groups is needed.

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And finally, the study is dedicated to all those parents considering newborn male circumcision.

"...Nature is a possessive mistress, and whatever mistakes she makes about the structure of the less essential organs such as the brain or the stomach, in which she is not much interested, you can be sure that she knows best about the genital organs."

Sir James Spence, 1950.

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**List of Abbreviations**

<b>American Academy of Pediatrics</b>	<b>AAP</b>
<b>Canadian Pediatric Society</b>	<b>CPS</b>
<b>Canadian Institute for Health Information</b>	<b>CIHI</b>
<b>Decisional Conflict Scale</b>	<b>DCS</b>
<b>District Health Council</b>	<b>DHC</b>
<b>National Center for Health Sciences (US)</b>	<b>NCHS</b>
<b>Decision Support Framework</b>	<b>DSF</b>
<b>Ontario Health Insurance Plan</b>	<b>OHIP</b>
<b>Regional Municipality of Ottawa-Carleton</b>	<b>RMOC</b>
<b>Urinary Tract Infection</b>	<b>UTI</b>

## Chapter One

### Introduction

*This chapter provides an introduction to the issues surrounding parents' decision making needs regarding neonatal male circumcision and provides the rationale for a needs assessment within this population.*

#### Problem

Neonatal circumcision is a high volume decision made by many parents of male infants. As well, after decades of debate and study, routine male circumcision remains controversial. Despite the delisting of circumcision from the Ontario Health Insurance Program (OHIP) schedule of benefits, and despite recommendations from the Canadian Pediatric Society (CPS) that circumcision is not medically indicated, circumcision rates in Canada remain at 30% (CIHI, 1996), with wide variations ranging from 1 to 65% in some regions. More recently, prophylactic circumcision as an elective, routine procedure has been questioned in the media, with journalists debating its efficacy (Kirkey, 1999; Stone, 1999; Douglas, 1998). This complex decision, about whether or not to circumcise, has the potential to create decisional conflict for parents. Little is known, however, about their decisional conflict or their decision making needs.

#### Purpose

This study, guided by the Ottawa Decision Support Framework (O'Connor et al., 1998a), proposed to: (a) describe the decision making needs of parents making choices about neonatal male circumcision, and (b) describe the needs of prenatal instructors who inform parents about options. The information was obtained to identify the sub-optimal elements of parents' decision making as a basis for developing educational materials for parents and their practitioners.

### Background to the Circumcision Decision

Circumcision of male infants varies widely around the world, with approximately 80% of the male population remaining non circumcised (Kim, Lee & Pang, 1999). The operation is uncommon in northern European countries, Central and South America, and Asia. In contrast, circumcision is common in Polynesia, North America and the United Kingdom; among Muslims and Jewish people; and among North and South American Indians, Australian Aborigines and African tribes (Holman, Lewis & Ringler, 1995). In 1970, 48% of the male population was circumcised in Canada; 24% in the United Kingdom; and 70% in Australia (CPS, 1996). After a sharp increase in the Canadian rate of circumcision in 1991 (from 35% to 42%), there was a slow decline to 30% by 1995. (CIHI, 1996).

Between 1985-1995, based on in hospital circumcision of infants younger than 28 days of age in Ontario, the provincial rate remained almost constant at 35%. However, there are significant regional variations in practice rates. Approximately 65% of newborn males within the Essex district health council (DHC) were circumcised compared to 1.6% in the Hamilton-Wentworth DHC (To, Feldman, Dick & Tran, 1996). Within the region of Ottawa-Carleton DHC, the percentage of circumcised newborn males remains at approximately 40%, slightly higher than the provincial rate (CIHI, 1996). Currently, the circumcision rate at the Ottawa Hospital (1998-99) is 33% of the total number of male births, demonstrating slight change in practice despite renewed questioning of an old procedure.

In the United States, circumcision rates have remained higher (~65-80%), possibly reflecting a greater emphasis on the perceived medical benefits (NCHS, 1995). The American Academy of Pediatrics (AAP) recently reevaluated its policy about circumcision, stating that,

**“Circumcision is not essential to a child’s well-being at birth, even though it does have some potential medical benefit. These benefits are not compelling enough to warrant the AAP to recommend routine newborn ( male) circumcision”, (Lannon,1999, p.686). In Canada, the CPS statement (1996) recommends that “Circumcision of newborns should not be routinely performed” (Fetus & Newborn Committee, p.769). However, the CPS recognizes that parents’ decision about circumcision may reflect their personal, religious or cultural values.**

**Until recently, empirical literature in North America supported circumcision as a method of reducing health risks in the following areas (a) penile problems; (b) sexually transmitted disease; (d) cancer of the penis; and (e) urinary tract infections (UTI) (Langer & Coplen, 1998, Tiemstra, 1999). A brief discussion follows about the anatomy and physiology of the foreskin and current evidence on outcomes with and without circumcision.**

**The prepuce or foreskin is an integral, normal part of the external genitalia, that forms the anatomical covering of the glans penis. The outer covering has a protective function of internalizing the glans, urethral meatus and the inner preputial epithelium, decreasing external irritation or contamination (Cold & Taylor, 1999; Gairdner, 1949). The prepuce is a specialized, junctional mucocutaneous tissue which marks the boundary between mucosa and skin. The fused mucosa of the glans penis and the inner lining of the prepuce separate gradually over years, as a spontaneous biological process. Parents of non circumcised infants should be made aware that manipulation and retraction of the immature foreskin, must be avoided to prevent scarring, bleeding, phimosis and psychological trauma. The unique innervation of the prepuce establishes its function as an erogenous tissue (Cold & Taylor, 1999).**

According to Cold and Taylor, circumcision involves the removal of normal, healthy, genital tissue from infants and children for religious, societal, or theoretical medical benefit. Although the amount of genital tissue removed is variable, the penile prepuce is removed in nearly all male circumcision. During the surgical procedure, before the prepuce has naturally separated, the foreskin must be detached from the glans penis with the concomitant risk of glandular excoriation and injury.

In Denmark, where circumcision is not widely practiced, the need for future circumcision is estimated to be 1.7% (Rickwood, 1999). In non circumcised male infants, the risk for urinary tract infections (UTIs) is reported to be 7 to 14 infants per 1000 versus 1 to 2 per 1000 in circumcised infants (To, Agha, Dick & Feldman, 1998). According to Mueller, Steinhardt and Naseer (1997), 75% of infants, regardless of circumcision status, who present with their first UTI under the age of 6 months are likely to have underlying genitourinary anomalies.

Complications associated with the surgical procedure of circumcision vary according to the reporting and diagnostic criteria employed. According to Niku, Stock and Kaplan (1995), the true incidence of postoperative complications after circumcision is unknown. American researchers, Ansell and Gee (1976) stated that the overall complication rate was found to be between 0.2 to 0.6%, while British researchers, Williams and Kapila (1993) concluded that a more realistic rate was 2 to 10%. Collectively, the risks include bleeding, pain and infection in the immediate postoperative phase to future complications such as meatal stenosis and poor cosmetic results.

Currently, practitioners remain polarized about circumcision, as evidenced by multiple studies on the advantages and disadvantages of the procedure. Many of these studies have been

reviewed and criticized not only for questionable, experimental designs, but also for encouraging the continued practice of circumcision on limited scientific evidence (Lauman, Masi & Zuckerman, 1997; Tiemstra, 1999). Most recently, To, et al. (1998) argued that the risk of developing a UTI in the first year of life is extremely low and that the magnitude of protection conferred by circumcision, may be less than previously estimated. The researchers suggested that in order to prevent one UTI in a male during the first year of life, 195 infant males would need to be circumcised, thereby exposing 2 to 10% of these infants to complications. In addition, new data have suggested that breastfeeding and rooming-in may offer added protection against UTIs (Pisacane, Graziano, Mazarella, Scarpellino, & Zona, 1992; Winberg et al, 1989). Regardless, many practitioners still support circumcision as a method of preventing UTIs in infants under one year of age (Craig, et al., 1996; Wiswell & Hachey, 1993; Wiswell, 2000). Despite the current recommendations and at the request of parents, many practitioners continue to perform routine circumcision, perceiving the surgery to be essentially safe and low-risk in the neonatal period.

The decision whether or not to circumcise a male newborn is one in which the parents must consider the advantages and disadvantages of the procedure and their personal values and expectations. The information on the advantages and disadvantages of either option may be difficult to assess accurately from many circumcision studies. Knowledge about the normal anatomy and physiology of the foreskin has been neglected in North American culture because the majority of the male population has been circumcised (Cold & Taylor, 1999). Concurrent with the debate about circumcision, is the controversy about the pain experienced by newborns. Diminishing infant pain during circumcision has been recognized as a necessary adjunct to the

procedure (Lander, Brady-Fryer, Nazarali, & Muttitt, 1997; Taddio, Katz, Ilersich & Koren, 1997). However, old attitudes may persist and circumcision pain may be dismissed by some parents and practitioners as trivial or minor.

While the current AAP and CPS policy statements do not support routine circumcision, these agencies are careful to add that there may be a small but potential medical benefit to the procedure. Parents' decisional conflict may be increased by: (a) the delisting of circumcision from the provincial health plan; (b) the lack of a medical consensus about the disadvantages and advantages of circumcision, and (c) the sociocultural issues surrounding the procedure. Clearly, the circumcision decision is complex. Yet, little is known about the decision making needs of parents, nor the optimal strategies for providing decision support.

### Organization of Thesis

This thesis is divided into five chapters. Chapter Two provides a critical review of previous research relevant to decision making and circumcision and a description of the conceptual framework on which the thesis is based. In Chapter Three, the study design, including pilot testing and sample size calculations, is described as well as the setting, data collection, measurement and plan for analysis. Chapter Four describes the results and a discussion of the results follows in Chapter Five.

## Chapter Two

### Review of Previous Research and Theory

*This chapter describes the search methods used, followed by a summary of the research surrounding parents' decision making needs regarding neonatal male circumcision and the types and efficacy of the decision support interventions. The conceptual framework of the study is outlined, including a chart illustrating the application of the framework to both parents and practitioners.*

#### Research Search Strategy

A computerized search of the published literature related to circumcision included the following data bases: Medline (1966 - 2000); Cumulative Index of Nursing and Applied Health, CINAHL (1983 - 2000); PsycInfo (1980-1999); ERIC (1985-1999); Cochrane data base and Internet sites located at the URL: [www.cirp.org](http://www.cirp.org) and <http://infocirc.org>

Since the data bases do not share an identical pool of index terms, each database was searched using a list of keywords appropriate to the particular database. Some examples of the strategies used are: MEDLINE (circumcision, neonatal, decision-making, postpartum education, decision support, maternal health education); and CINAHL (circumcision, patient advocacy, newborn care, consumer satisfaction, informed consent). The Internet sites generated lists of recently published literature as well as Canadian and American statistics on circumcision rates from evidence based sources. In addition, a hand search was carried out by examining reference lists of the relevant published material.

### Previous Interventions Examining Parental Education and Decision Making

Although much of the literature in North America focussed on the practice of routine circumcision as a method of disease prevention, a few researchers began to seek answers for the continued popularity of elective circumcisions of newborn males. Despite the AAP initial statement (1975), the majority of male infants (90%) born in the United States, continued to be circumcised. Studies done before 1989 showed that few parents were aware of the medical debate regarding circumcision and most based their choice on concerns relating to hygiene and appearance (Brown & Brown, 1987; Lovell & Cox, 1979).

Five studies tested formal educational interventions aimed at discouraging circumcision and increasing parental information about circumcision (Christensen-Szalanski, Boyce, Harrell & Gardner, 1987; Enzenauer, Powell, Wiswell, & Bass, 1986; Herrera, Cochran, Herrera, & Wallace, 1983; Maisels, Hayes, Conrad & Chez, 1983; Rand, Emmons & Johnson, 1983). Only Enzenauer et al. showed a reduction in the circumcision rate (70 versus 90%), noting that the frequency rose again after completion of the study. None of the studies showed any improvement in parents' understanding of the medical issues, despite a wide range of educational levels.

Maisels, Hayes, Conrad, and Chez (1983) studied the effect of giving mothers prenatally, comprehensive written information about circumcision based on the recommendations of the AAP. In the control group, mothers did not receive the written information. The researchers noted that the provision of written information did not appear to have any significant effect on the understanding of the parents with regard to the harms and benefits of circumcision. The

study also concluded that providing written information to mothers in the third trimester of pregnancy has little role in the decision-making process.

In a randomized study, Rand, Emmons, and Johnson (1983) questioned whether a spoken educational intervention would reduce the rate of circumcision. The study concluded that when mothers were verbally presented with an accurate summary of the risks and potential advantages of circumcision, many chose not to circumcise their sons, even when they had previously decided in favor of the procedure. However, the investigators noted that the educational intervention was most effective when the infant's father was not circumcised.

Herrera, et al. (1983) considered whether proper medical counselling in higher socioeconomic groups among highly motivated couples with higher education would make a difference in the circumcision rate. In a matched, randomized study, the two groups were compared, Group 1 receiving special counselling about the risks and benefits of circumcision according to the AAP guidelines and Group 2, the control receiving the standard care. The information was given at the seventh month of pregnancy and it was followed by a group discussion. Parents were encouraged to research the procedure further and to seek the advice of their doctors if they wished. The findings suggested that there were no differences between the groups in the circumcision rate and that counselling in the third trimester did not make a difference. The study did not disclose the fathers' circumcision status, a known variable in predicting circumcision frequency.

In a random controlled study, using videotape counselling, parental requests for circumcision decreased (Enzenauer, Powell, Wiswell, & Bass, 1986). The study used two groups, both groups receiving counselling within 36 hours of delivery. In the experimental

group, in addition to counselling by a resident physician, all parents of male newborns were required to view two videotapes, one describing the procedure and the other summarizing the factors relating to neonatal circumcision. The researchers found that the videotape counselling was effective not only in circumcision rate reduction but also in the reduction of physician time required to ensure informed consent. However, Enzenauer et al. noted a gradual increase in the circumcision frequency rate after the systematic videotaped counselling was discontinued.

Christensen-Szalanski et al. (1987) claimed that an insufficient knowledge of the medical complications associated with circumcision was one reason to account for parents' persistence with circumcision. The researchers also reasoned that increasing the amount of risk information provided to parents would increase their satisfaction with their care and alter their decision to circumcise their sons. All mothers in the study received partial disclosure about the risks of circumcision. The mothers were then subdivided into two additional groups, Group 1 receiving written information and Group 2 receiving verbal comprehensive disclosure. Providing mothers with written and verbal comprehensive disclosure of risk information had little effect on the mothers' decision to circumcise their sons. The researchers concluded that mothers who wished to have their sons circumcised ignored the medical information and instead based their decision on social, traditional and religious reasons.

### Informed Consent and Decision Making

According to the CPS (1996) and the AAP (1999) circumcision is considered elective surgery, requiring full disclosure of the benefits and risks in order to give parents accurate and unbiased information. Both agencies expect parents to have an opportunity to discuss their decision with a health care provider in order to make an informed choice. However, the

literature suggests that many parents do not receive adequate, medical information about the risks and benefits of both circumcising and not circumcising or the need for analgesia during the procedure (Ciesielski-Carlucci, Milliken, & Cohen, 1997; Tran & Giacomantonio, 1996) . Parent comprehension and understanding of medical advantages and disadvantages are frequently overlooked in many discussions and parents continue to make a choice about circumcision based on incomplete information (Ciesielski-Carlucci, Milliken, & Cohen, 1997; Tiamestra, 1999). Berger & Cook (1998) concluded that perceived learning needs of health care providers (nurse practitioners, physicians, and nursing staff) differed in some categories from the actual desires of mothers in prenatal clinics. Christensen-Szalanski et al. commented on the differences between the physicians' estimate of the seriousness of the complications of circumcision and those expressed by the mothers. When deciding which complications to discuss with parents, the authors suggested that physicians base their discussions on the frequency and perceived seriousness of the complication.

In a prospective survey of parents immediately after making the circumcision decision regarding their reasons for the decision, Brown and Brown (1987) examined the importance of social issues. Although the findings revealed a combination of medical and social concerns, social issues such as genital congruence with father and siblings appeared to have a greater influence on the decision. Brown and Brown concluded that because of the strong base of the circumcision decision in social issues and cultural traditions, the decision is more emotional than rational.

### Parents' Desire for Information about Circumcision

Although parents may make decisions about circumcision based more on sociocultural reasons than on scientific evidence, newer studies suggest that parents continue to want detailed information about circumcision (Berger & Cook, 1998; Moran, Holt, & Martin, 1997). Moran et al. (1997) found that both primiparas and multiparas women shared an equal desire for information on circumcision. Bean & Egelhoff (1984) noted that 61% of mothers still desired information about circumcision, despite having already decided in favor of the surgery.

### Timing of Decision Making and Information

An important factor when considering informed decision making and circumcision, is the timing or staging of the discussion about advantages and disadvantages (Deber, 1994; O'Connor, et al., 1998a). Christensen-Szalanski et al. noted that more detailed information was not always desired by mothers, resulting in decreased confidence in their choice and resentment toward the physician for creating doubts. The mothers in the study were questioned 24 hours prior to making a decision about circumcision, perhaps reflecting the importance of timing when giving new information.

Two studies confirmed that the decision to circumcise is made even before becoming pregnant and well before any physician discussion (Bean & Egelhoff, 1984; Tiemstra, 1999). Several studies noted that a single discussion with a health care professional in the last trimester had little or no effect on the circumcision decision (Ciesielski-Carlucci et al. 1997; Herrera et al., 1983; Rand, Emmons & Johnson, 1983; Tiemstra, 1999). Tiemstra concluded that 80% of parents had made the decision to circumcise before discussing the surgery with their health care provider.

### Practitioner's Role in the Decision

Health care provider bias and knowledge deficits have been found to affect both the number of circumcisions performed and the quality of information provided (Christensen-Szalanski et al., 1987; Ciesielski-Carlucci et al. 1997; Patel, 1968; Stein, Marx, Taggart & Bass, 1982. Walton, Ostbye, and Campbell (1997) noted that many parents who choose circumcision acquire their beliefs about the medical benefits from family and friends rather than their doctors. The researchers also claimed that although physicians presented a neutral view to parents about circumcision, those physicians who expressed opinions, did influence outcomes. However, in another study, Tiemstra (1999) noted that when the practitioner's discussion was neutral in tone, parents claimed that the discussion did not change their opinion about circumcision, regardless of the information.

In a survey, Christensen-Szalanski et al. questioned physicians about their method of providing informed consent to their patients. Physicians were asked about the frequency with which they informed parents about 13 possible medical complications of circumcision and three possible harms of not being circumcised. The study showed that physicians routinely informed parents about only three medical complications associated with circumcision and none of the possible risks associated with not being circumcised.

Stein et al. (1982) surveyed physicians' and parents' attitudes, knowledge and personal factors related to circumcision in the newborn period. Two questionnaires were designed to elicit information from primary care practitioners and parents of male infants, randomly selected from the practices of physicians in private practice. The study results indicated that routine neonatal circumcision was favoured more often by older, male, and circumcised physicians.

Physicians' knowledge about the normal anatomy of the infants' foreskin was inadequate. In addition, the study suggested that parents rarely perceived physicians as influential in the decision-making process. Instead, the fathers' circumcision status and parental belief in medical indications were positively related to the decision to circumcise.

Although many parents seek advice from sources other than health professionals, they still want information about circumcision in order to make an informed choice that is consistent with their values. However, the level of knowledge acquired during a discussion with a health practitioner often does not meet the criteria for informed consent. Information, written or verbal, about the harms and benefits of circumcision given to the mother during the last trimester of pregnancy, appear to have little impact on the decision. More important, fathers' circumcision status and a parental belief that there are medical indications for circumcision, are positively related to the decision to circumcise a male newborn. In summary, the literature confirms that there are unanswered questions regarding what information parents want, who should provide it and the ideal time to share that information.

### Conceptual Framework

The Decision Support Framework (DSF), developed by O'Connor et al., (1998) was chosen for this study. The theoretical structure for the DSF is based on expectancy value theories in economics (Keeney and Raiffa, 1976); cognitive psychology theories (Tversky & Kahneman, 1981); decisional conflict theories (Janis & Mann, 1979); Ajzen and Fishbein's theory of planned action (1980); and social support theories (Feather, 1980; Norbeck, 1988; Orem, 1980). The framework is outlined in Figure 1.

**Figure 1. Decision Support Framework (DSF)**

The variables in italics are those that were investigated in the study.

<b>Assess Needs (Determinants of Decision)</b>	<b>Provide Decision Support</b>	<b>Evaluate</b>
<p><b>Perceptions of Decisions</b>  <i>knowledge</i>  <i>expectations</i>  <i>values</i>  <i>decisional conflict</i>  <i>stage of decision making</i>  <i>predisposition</i></p> <p><b>Perception of Others</b>  <i>perceptions of other ' opinions &amp; practice support</i>  <i>pressures</i>  <i>role in decision making</i></p> <p><b>Resources to Make Decision</b>  <u>Personal</u>  <i>previous experience</i>  <i>self-confidence</i>  <i>motivation</i>  <i>skill in decision making</i>  <u>External</u>  <i>support (information, advice, emotional, instrumental, professional help) from social networks and agencies</i></p> <p><b>Characteristics</b>  <i>client: age, sex, marital status, education, occupation, culture, locale, medical diagnosis &amp; duration, health status,</i>  <i>practitioner: age, sex education, specialty, culture, practice locale, experience, counseling style</i></p>	<p><b>Provide access to information</b>  <i>health situation</i>  <i>options</i>  <i>outcomes</i>  <i>other's opinions and choices</i></p> <p><b>Re-align expectations of outcomes</b></p> <p><b>Clarify personal values for outcomes</b></p> <p><b>Provide guidance / coaching in:</b>  <i>steps in decision making</i>  <i>communicating with others</i>  <i>handling pressure</i>  <i>accessing support &amp; resources</i></p>	<p><b>Decision Making</b>  <i>reduced decisional conflict</i>  <i>improved knowledge</i>  <i>realistic expectations &amp; norms</i>  <i>clear values</i>  <i>agreement between values &amp; choices</i>  <i>implementation of decision</i>  <i>satisfaction with decision making</i></p> <p><b>Outcomes of Decision</b>  <i>persistence with choice</i>  <i>improved quality of life</i>  <i>reduced distress</i>  <i>reduced regret</i>  <i>informed use of resources</i></p>

### **Rationale for the Use of the Framework**

The DSF was developed for health decisions that: (a) are stimulated by a new circumstance, diagnosis or developmental transition; (b) require careful deliberation because of the uncertain and/or value-sensitive nature of the benefits and harms; and (c) need relatively more effort during the deliberation phase than the implementation phase. These criteria accurately reflect the nature of decision making regarding neonatal circumcision.

The DSF describes a process of providing to both parents and practitioners decision support including: (a) assessing the determinants of a decision to identify needs; (b) providing the decision support interventions; and (c) evaluating the decision support by examining the quality of the decision process and the outcomes of decisions (O'Connor et al., 1998). In the proposed study, the first phase of the framework was most relevant in planning a needs assessment from the perspective of parents and practitioners. A definition of the determinants of the DSF are outlined in Figure 2.

### **Assessing the Determinants of the Decision to Identify Needs**

The DSF describes the key factors that influence a decision including the parent's and practitioner's: demographic, clinical and practice characteristics; perceptions of the decision; perceptions of important others involved in the decision; and personal and external resources to make and implement a choice. According to the DSF, a parent may choose circumcision for their infant son because: (a) it is the expectation that it will lead to valued outcomes (e.g. genital congruence, cleanliness); (b) others whose opinions are valued by the family (e.g. relatives, health care professionals) consider it to be a desirable option; and (c) the parent has the

necessary personal resources and external assistance to make and implement the choice. The variables used in this study are outlined in Figure 1.

## **Figure 2. Definitions of Determinants of Decisions in the Ottawa Decision Support Framework**

### **Perceptions of the Decision**

- decisional conflict - uncertainty about course of action to take
- knowledge - cognizance of the health problem or situation, options and outcomes
- expectations - perceived likelihood or probability of outcomes of each option
- values - desirability of personal importance of outcomes of options
- stage of decision - phase of decision making in the context of stages of change: precontemplation (not thinking about the change or choices); contemplation (considering the options); preparation (taking steps toward change, maybe considering options); action (change for less than 6 months); maintenance (change for at least 6 months) perceptions of others opinions

### **Perceptions of Important Others regarding the Decision**

- and practices - perceptions of what others decide or what others think is the appropriate choice. For the client, important others may include their spouse, family, peers, and practitioner(s). For the practitioner, it may include client, professional peers and personal network.
- pressure - perception of persuasion, influence, coercion from important others to select on alternative
- support - informational, emotional, and tangible help from important others to bolster and sustain decision making
- role in decision making - the way a participant is or wants to be involved in decision making with others; do they wish to make a choice themselves after considering other opinion, do they want to share decision making with someone else, do they want others to make the decision after considering their opinion

### **Resources to make the decision**

#### **Personal**

- experience - previous exposure to the situation, options, outcomes, decision making process
- self-confidence - belief in one's abilities in decision making, including shared decision making
- motivation - readiness and interest in decision making, including shared decision making
- skills - abilities in making and implementing a decision
- other - instrumental and financial capabilities to implement choices

#### **External**

- type: - assets from others that are required to make and implement the decision
- source: - availability and access to information, advice, emotional support, instrumental help, financial assistance, and health and social services
- source: - social networks, professional networks, support groups, voluntary agencies and formal health care, education and social sectors

### **Characteristics**

- client: - age, sex, education, marital status, ethnicity, occupation, locale, diagnosis and duration of condition, health status (physical, emotional, cognitive, social)
- practitioner: - age, sex, ethnicity, clinical education and specialty, practice locale, years of experience, counseling style

### Providing Decision Support to Address Needs

The goal of decision support is to improve the quality of decision making by addressing the modifiable determinants of decisions that are sub-optimal such as: inadequate knowledge, unrealistic expectations of outcomes, unclear values for outcomes, unwanted pressure, inadequate support; and inadequate personal and external resources to make an informed decision. For example, parents and practitioners may lack sufficient, current information about the advantages and disadvantages of circumcision. One parent may favor circumcision while the other parent may not, leading to increased decisional conflict and marital stress. Practitioners may feel that their counsel about circumcision appears to have little impact on the decision and consequently, they may resent the time spent discussing this issue.

Decision support may include the early dissemination of information in prenatal classes about the current knowledge of the advantages and disadvantages of circumcision. Detailed outcomes and probabilities about circumcision and not circumcising may help parents realign their expectations. Parents may understand their values about circumcision more clearly if they engaged in values clarification exercises to consider the personal importance they place on each advantage and disadvantage. By addressing these factors early in pregnancy, parents may be better prepared to discuss their decision with a practitioner, thereby reducing decisional conflict and improving decision making for both.

### Evaluating Decision Support

The DSF distinguishes between quality decision making and quality outcomes. O'Connor et al., (1998a) defines a high quality decision as informed, consistent with personal values, and acted upon in which the decision maker expresses satisfaction with the process and the decision.

Decision support should improve decision making by: (a) improving knowledge of alternatives, advantages and disadvantages, clarifying personal values and promoting agreement between values and choice; (b) creating realistic expectations; (c) reducing decisional conflict; and (d) increasing satisfaction with the decision making. An improved process of decision making may affect outcomes such as regret or distress from the consequences of the choice. For example, if a parent chooses circumcision, she may anticipate regret about the painful aspects and the irreversible nature of the surgery. If a parent chooses not to circumcise her son, the child may develop complications that require surgery later in childhood. By providing adequate decision support that prepares parents for possible consequences of options, there may be a positive impact on the outcomes by reducing stress from the consequences, reducing regret, and using resources appropriately (O'Connor & Jacobsen, 1998).

#### Previous use of the framework

The DSF incorporates the factors that have been identified in the process of patient decision making. The framework has been used in several studies (Davidson & Brundage, 1994; O'Connor, Tugwell & Wells, 1994; Health Care Research Group, 1992; O'Connor et al., 1998a, 1999a, 1999b). Evidence of the validity of the DSF has been established with the confirmation that the determinants are frequently sub-optimal and can be improved with decision supporting interventions such as decision aids. For example, decision aids that provide information, values clarification, and guidance in deliberation improve knowledge, create realistic expectations, clarify personal values and make patients feel supported.

The present study is the first time the DSF has been used for the circumcision decision. A needs assessment is required before interventions can be developed. Specifically, the

**variables under investigation in this study according to the DSF included: perceptions of the decision; perceptions of important others regarding the decision; personal and external resources to make and implement the decision; and practitioners and client characteristics.**

**Since there were no studies found using a framework to examine the needs of parents and practitioners regarding decision making about circumcision, the results of the current study make an important contribution. Such information would be helpful in planning interventions to meet the needs of both recipients and providers of decision support.**

## Chapter Three

### Method

*This chapter describes the method used to pilot test and conduct a needs assessment using a specifically designed questionnaire for parents considering circumcision and prenatal instructors who assist them . The research design, the study population, recruitment and data collection procedures are described.*

#### Design

A needs assessment was conducted, employing a cross-sectional survey of mothers and fathers, and their prenatal instructors regarding decision making about circumcision.

According to Witkin and Altschuld (1995), “ a need, as a noun, refers to the gap or discrepancy between a present state (what is) and a desired end state, a future state, or condition (what should be)...” (p.4). Polit and Hungler (1995) state that a needs assessment represents an effort to provide a decision or policy maker with information for action. Within organizations, needs assessment are commonly used to gather data for estimating needs and to provide information for service and/or care improvement. Because contemplation about the circumcision decision takes place during the antenatal stage (Bean & Egelhoff, 1984; Ciesilski-Carlucci et al.1996; Maisels et al., 1984; Tiemstra,1999), the focus was on parents at that time and prenatal instructors who were in a position to support decision making.

#### Parent Study - Sample and Setting

A convenience sample of 88 mothers and 67 fathers was recruited from prenatal classes conducted by the Regional Municipality of Ottawa Carleton health department. The health department offers prenatal classes to women and their partners in the first and second trimester

and who are between the ages of 20-40 years or older. The classes of eight to ten couples, are offered in a series of seven sessions, providing education about healthy pregnancy, labour and birth outcomes with an emphasis on the prevention of a low birth weight infant. Information regarding circumcision occurs during the later classes in addition to the fundamentals of new baby care. In a study of local participation, Stewart, Ramsingh, Potter & Nadon, (1993) estimated that 85% of the attendees in prenatal classes are first time parents. Inclusion criteria for this current study were: (a) an ability to read and write English; and (b) voluntary, informed consent to participate.

#### Method of Recruitment

Information about the study was given to the prenatal instructors by the program director. Once administrative and ethical approval had been received, the researcher contacted each prenatal instructor for permission to visit and distribute the questionnaires during the class. Each instructor allowed time for questionnaire completion during the class session and the researcher was able to collect the completed questionnaires.

#### Circumcision Questionnaire

A standard questionnaire, (Appendix B), used to elicit the decision making needs of parents, was adapted for the circumcision decision (O'Connor et al. 1993; O'Connor, 1995; O'Connor et al., 1998a). The questionnaire, organized according to the DSF, elicited parents': (a) perception of the decision; (b) perception of others; (c) resources to make a decision; and (d) characteristics. All questions were reviewed for face and content validity by Dr Annette O'Connor, Dr Barbara Davies and MJ Jacobsen. The variables and measures used in the questionnaire are outlined Figure 3.

**Figure 3. Measurement of variables in the decision support framework**

<b>Perceptions of Decision</b>		
<b>variable</b>	<b>parent measures</b>	<b>prenatal instructor measures</b>
knowledge	(a) 10 item questionnaire using a true, false, unsure format (b) informed subscales of DCS using a 3 item Likert scale	personal perception of disadvantages and advantages of circumcision
expectations	probability scale ranging from 0 to 1000: using 'all' to 'none', 'don't know'	
values	(a) 11 point rate scale anchored by 0 (not important) to 10 (extremely important) (b) values subscale of DCS: 3 item Likert scale	
decisional conflict	uncertainty subscale of the DCS: 3 item Likert scale	perception of parent's difficulty in making difficult choices
stage of decision making	6 stages moving from precontemplation to active contemplation to making a decision	
choice predisposition	15-point scale anchored by the options 'yes' circumcision and 'no' circumcision with midpoint 'unsure'.	
<b>Perception of Others</b>		
role in decision making	preferred role: in relation to the family and health care practitioner.	usual role in decision making, others involved in the decision
pressure and support	support subscales of DCS: 3 item Likert scale	
<b>Resources to Make Decision</b>		
personal & external	sources of information	perception of parents' readiness and interest in decision making; current provision of information and support; barriers and facilitators to providing support; perception of useful strategies and delivery mechanisms; preferred sources of information; professional networks confidence in knowledge
<b>Characteristics</b>		
	sex, age; education; language; religion; gestation; parity; knowledge of baby's gender; previous experience with circumcision; father's circumcision status;	experience teaching; education; knowledge of circumcision

### Measurements - Perception of the Decision

In section A of the questionnaire, “My stage of decision making”, parents were asked whether they had begun to think about circumcision. The responses (6) ranged from (haven't begun to think about choices) to (have already made a decision and are unlikely to change your mind). Section B of the questionnaire elicited parents' choice predisposition by asking their opinion about circumcision at that moment. The item was a 15 point scale anchored by the options 1 = yes circumcision, 15 = no circumcision) and unsure situated in the centre. Responses from the 15 point scale were reclassified into 3 categories; (a) favour circumcision (1-5); (b) unsure (6-10); and (c) favour no circumcision (11–15). This question has been used in other populations considering options for menopause, genetic testing, end stage chronic obstructive pulmonary disease (COPD), and treatments for breast cancer. Test retest reliability coefficients exceed 0.90.

Section C, the decisional conflict scale (DCS) assessed: the uncertainty parents felt about the decision and factors contributing to the uncertainty, including feeling informed about options, being aware of personal values, and feeling supported in decision making. The responses to each statement were scored from one (strongly agree) to five (strongly disagree). Scores were summed and divided by the number of items. Therefore, a total score of one indicated low decisional conflict and a score of five indicated high decisional conflict. According to O'Connor (1997), the scale norms identify those groups who delay choices to have average decisional conflict scores above 2; those who make choices have average scores of 2 or less. The reliability and validity of the scale have been tested previously in studies on decision making in several patient populations, such as options for menopause, genetic testing, end stage

COPD and treatments for breast cancer (O'Connor, 1995). The internal consistency alpha coefficients range from 0.78 to 0.92 and the scale discriminates between those who delay their decision or are unsure what to do (O'Connor, 1999).

Section E elicited parents' fundamental knowledge about the practice of circumcision, care of the foreskin, and factors associated with both conditions. The knowledge scale consisted of 10 items worth 10 points and a response format consisting of (true, false or unsure). A percentage based on the number of correct responses was calculated for each group of respondents. Content validity was reviewed by Dr Michael Leonard, Chief of Pediatric Urology, Children's Hospital of Eastern Ontario. A similar approach has been used for other populations such as options for menopause, genetic testing, end stage COPD and treatments for breast cancer (O'Connor, 1995).

Section F and G elicited parents' expectations (perceived likelihood) of complications for each option (circumcision or no circumcision). The sections were organized according to the common outcomes for a non circumcised infant and a circumcised infant from published literature. Probability scales were used to assess expectations of each item. They ranged from 0 (none) to 10 (all) and a single item (don't know). The number of intervals depends on the degree of precision required for a particular complication (O'Connor & Pennie, 1995). This type of scale has been used for Expectations were defined as realistic according to its correspondence to the published evidence. A summary score indicated the percentage of expectations that were realistic. This type of scale has been used for populations considering options for menopause, atrial fibrillation, and schizophrenia. Alpha coefficients exceed 0.70.

Section H elicited information about parents' values or personal importance of the benefits and risks, regarding their decision. Respondents were asked to respond to nine potential benefits and risks, using an 11 point rating scale ranging from 0 (not at all important to me) to 10 (extremely important). A similar approach has been used in other populations such as options for menopause, genetic testing, end stage COPD and treatments for breast cancer.

Questions 10 and 11 were open ended, eliciting parents' most important reason in their decision. The qualitative information was recorded into common categories.

#### Measurement - Perception of Important Others

Section D elicited parents' preferred role in decision making. Respondents were asked who within their family was involved in the decision while a second question elicited the actual role parents' preferred in making the decision. In section C, the decisional conflict scale, perceived problems with support and pressure were measured in the support subscale.

#### Measurement - Resources to Make a Decision

The final section I, elicited parents' preference for sources of information about the circumcision decision.

#### Sample Size

Statistics from the health department indicated that there were 1215 couples and 991 couples attending prenatal classes in 1997 and 1998 respectively. Gower and Kelly (1988) suggest that calculations for survey sample size include the desired margin of error, adjustment for non-response and the confidence interval (Appendix A). Using the formula provided by Gower and Kelly, the current study needed 88 participants for a 95% confidence interval, a

margin of error +/- 10% and a response rate of 75%. Therefore, 88 mothers and as many fathers as were present were recruited.

### Data Analysis

Using a statistical package (SPSS-9), quantitative data were coded and entered. The data from the parent questionnaire, were summarized with descriptive statistics including means, standard deviations, frequencies, and percentages and 95% confidence intervals. Mothers' and fathers' responses were analysed separately and each group was examined according to the fathers' circumcision status. Qualitative data obtained from parents' opinion were analysed for content and organized according to frequencies of common categories.

### Ethical Considerations

Administrative approval was obtained from the department head of the Infants and Children section at the health department. In addition, the proposal was examined by both the Methods Review and Ethics committees, before granting approval. The health department believed the participants to be non vulnerable adults and as such deemed completion of the questionnaire to be consent. The researcher was responsible for administering and collecting all data. The participants were offered the opportunity to receive the final study results.

There were no anticipated risks for the participants. However, the health department questioned whether the questionnaire would raise concerns for the participants. Consequently, before receiving approval for data collection, a pilot study of 14 mothers and one father was conducted asking specifically about the duration, clarity and any personal concerns generated by the questions (Appendix E). During the pilot study, one questionnaire per couple was distributed to allow parent collaboration. The results of the pilot study indicated that the questionnaire

took as little as five minutes and as long as 20 minutes to complete. The mean was 11 minutes. None of the pilot study participants expressed personal concerns or clarity problems from completing the questions.

At the end of the questionnaire, a resource page for the CPS position statement and web site was made available to all parents. Participants were encouraged to discuss any additional concerns with their health practitioner. The researcher remained available to answer any questions after parents had completed the questionnaire. In addition, the researcher made her phone number and that of the health department available to the parents.

#### Practitioner Study - Sample

A convenience sample of 10 prenatal instructors who were interested in participating, was recruited from the health department.

#### Procedure

The program manager circulated an invitation to participate in the study to all prenatal instructors at the health department (Appendix C). Prior to the distribution of the invitation, the investigator had an opportunity to meet all prenatal instructors at a regularly schedule meeting. At that time, information and the purpose of the study was shared with the group. The researcher then obtained phone numbers of the prenatal instructors and arranged a convenient time for an interview. In addition to prearranged interviews, some prenatal instructors asked to complete the questionnaire at the same time as the parents completed the parent questionnaire.

#### Prenatal Instructor Questionnaire

The questionnaire, organized according to the DSF, elicited prenatal instructors': (a) perception of the decision; (b) perception of others; (c) resources to make a decision; and (d)

characteristics (Appendix C). The 14 item prenatal instructor's questionnaire was divided into five sections. The questionnaire combined opened ended questions, as well as some check boxes for ease of answering. The content of the prenatal instructor questionnaire was reviewed by MJ Jacobsen. The format of the questionnaire was based on previous needs assessment questionnaires, developed by O'Connor and Jacobsen.

#### Measurement - Perception of the Decision

Prenatal instructors were asked whether the circumcision topic is discussed and whether this was a difficult decision to make. In open ended questions, the participants were asked to expand on their responses. They were also asked to explain their opinion of the advantages and disadvantages of circumcision.

#### Measurement - Perception of Others

Prenatal instructors were asked to indicate their usual role and others in the decision making process. In addition, the instructors were asked to describe the facilitators and barriers to providing decision support.

#### Measurement - Resources

Prenatal instructors were questioned about parents' skill at obtaining information pertinent to the decision. They were asked to list their preferred sources of decision support and information.

#### Measurement - Characteristics

The practitioner characteristics included: experience teaching; education; professional knowledge; and knowledge about the decision.

### **Data Analysis**

Descriptive statistics, such as frequencies, were used to describe practitioners' demographic characteristics. Content analysis was used for the qualitative data derived from the open ended questions.

### **Ethical Considerations**

The investigator obtained informed consent from the participating prenatal instructors. The participants were offered the opportunity to receive the final study results. In addition, the CPS position statement and web site were made available to all prenatal instructors after completion of the questionnaire.

## Chapter Four

### Results

*This chapter presents the responses to the needs assessment questionnaires of both parents and prenatal instructors. The chapter begins with a description of the demographic characteristics of the parent sample, followed by a description of the variables measured according to the Decision Support Framework. Next, the prenatal instructors are described and their responses to the questionnaire are presented.*

#### Parent Survey

**Response Rate.** Participants were recruited from May 18, 2000 to July 11, 2000. Of those approached to participate, two couples declined participation stating, “We don’t believe in circumcision”. The total sample included 67 fathers and 88 mothers, of which 66 were couples and eight were mothers attending without partners. The total sample includes the 15 participants from the pilot study, of which 14 mothers and one father responded.

**Demographic and Clinical Profile.** The participant characteristics are detailed in Tables 1-3. The modal respondent in this survey, was between 26 to 30 years of age, had a university degree, was Roman Catholic, spoke English at home and was expecting their first child. In addition, with a mean gestation of 21 weeks, the majority did not know the sex of their unborn infant. Almost three quarters (73.8%) of all fathers were circumcised.

Table 1. Demographic profile of mothers and fathers attending prenatal classes

FATHERS				MOTHERS			
mean age=32.2 (SD=5.37)				mean age=30.1 (SD=4.49)			
Age (years)	Freq (n=66)	(%)	CI	Age (years)	Freq (n=87)	(%)	CI
20 - 25	5	7.6	2.8-17.3	20 - 25	12	13.8	7.6-23.2
26 - 30	27	40.9	20.7-53.0	26 - 30	39	44.8	34.3-55.8
31 - 35	15	22.7	13.5-34.5	31 - 35	25	28.7	19.8-39.6
36 - 40	15	22.7	13.5-34.5	36 - 40	10	11.5	6.8-21.9
41 - 46	4	6.1	1.9-15.3	41 - 42	1	1.2	0.1-7.1
<b>Parents' Education</b>							
< High School	0	0		< High School	1	1.1	0.1-7.1
High School / Trade School	7	10.6	4.9-21.8	High School / Trade School	11	12.5	6.7-21.7
Some College / Some University	11	16.7	9.3-29.1	Some College/ Some University	11	12.5	6.7-21.7
University / College degree	48	72.7	59.0-82.1	University / College Degree	65	73.9	63.2-82.3
<b>Parents' Religious Affiliation</b>							
Protestant	16	26.2	16.2-39.3	Protestant	22	26.8	17.9-37.9
Roman Catholic	26	42.6	30.3-56.0	Roman Catholic	38	46.3	35.4-57.6
None	13	21.3	12.3-34.0	None	18	22	13.9-32.7
Other	6	9.9	4.1-20.9	Other	4	4.9	1.6-12.7
<b>Language spoken at home</b>							
English	50	74.6	62.3-84.1	English	74	84	74.4-90.7
French	8	11.9	5.7-22.7	French	7	8	3.5-16.2
Other	9	13.5	6.7-24.5	Others	7	8	3.5-16.2

**Table 2. Mothers' gestational characteristics.**

<b>Mothers' first pregnancy</b>			
Variable	Frequency	%	CI
no	8	9.1	4.3-17.8
yes	80	90.9	83.6-96.4
<b>Mothers' gestational age (weeks pregnant) mean=21.36 (SD=3.43)</b>			
14-20 weeks	37	42	31.7-53.0
21-25 weeks	40	45.5	34.9-56.4
26-28 weeks	11	12.5	6.7-21.7
<b>Mothers' known gender of unborn infant (do you know?)</b>			
not known	62	70.5	59.6-79.5
known	26	29.5	20.5-40.5
<b>Mothers' known gender of unborn infant (boy/girl)</b>			
boy	17	19.5	12.1-29.7
girl	8	9.2	4.3-17.8
not known	62	71.3	60.4-80.2

**Table 3. Fathers' circumcision status**

<b>FATHERS (n=67)</b>				<b>MOTHERS (n=88)</b>			
Variable	Freq (n=65)	(%)	CI	Variable (spouse)	Freq (n=88)	(%)	CI
Circumcised	48	73.8	61.2-83.6	Circumcised	66	75	64.4-83.4
Not circumcised	17	26.2	15.7-37.7	Not circumcised	22	25	16.6-35.6

**Stage of Decision Making.** Mothers' and fathers' stage of decision making is outlined in Table 4. At least a third of the fathers and mothers reported having made a decision, stating they would not change their minds. Nearly half of the parents reported that they had already given the decision some consideration. The percentages were similar in the stage of decision making between parents whose spouse was circumcised or not circumcised.

**Table 4. Parents' stage of decision making**

Variable	FATHERS (n=67)				MOTHERS (n=88)			
	Fathers n=65		Fathers who are circumcised (n=48)		mothers n=86		mothers whose spouse is circumcised (n=65)	
not thinking about it	9	13.8%	5	10.4%	7	8.1%	4	6.2%
not thinking about it but am interested	7	10.8%	5	10.4%	7	8.1%	4	6.2%
considering options	14	21.5%	12	24%	18	20.9%	17	26.2%
close to making a decision	4	6.2%	4	8.3%	1	1.2%	1	1.5%
made a decision but willing to reconsider	7	10.8%	5	10.4%	16	18.6%	12	18.5%
made a decision and will not change mind	24	36.9%	17	35.4%	37	43%	27	41.5%

**Current Opinion about Circumcision.** Parents' current opinion about circumcision is detailed in Table 5 below and Figure 4 (Appendix F). Nearly three quarters of all fathers and over half of all mothers favoured circumcision. Less than one in five were unsure what to do. Whereas 90% of fathers who were circumcised expressed a desire to circumcise, 76% of mothers whose spouse was circumcised had a similar desire. The breakdown of responses to the 15 point scale is summarized in Figure 4 (Appendix F).

**Table 5. Parents' opinion about circumcising a son**

variable	FATHERS (n=65)		Fathers who are circumcised (n=48)		MOTHERS (n=87)		mothers whose spouse is circumcised (n=66)	
favours circumcision	48	73.8%	43	89.6%	52	59.8%	50	75.8%
unsure	6	9.2%	5	10.4%	15	17.2%	10	15.2%
favour no circumcision	11	16.9%	0	/	20	23%	6	9.1%

When agreement between pairs of mothers and fathers was analysed, there was 70.8% agreement, as shown in Table 6. Only four pairs disagreed widely. In three cases, the father said "yes" and the mother said "no". In one case, the father said "no" and the mother said "yes". For the remaining disagreements, one of the pairs had checked in the "unsure" range, whereas the other checked closer to a specific option. In nine of these cases, the father was more in favour of circumcision and the mother was "unsure".

**Table 6. Agreement between Pairs of Mothers and Fathers on Opinion regarding Circumcision**

Variable	Fathers			
	favour circumcision (n)	unsure (n)	favour no circumcision (n)	total (n)
<b>Mothers</b>				
favour circumcision	37	3	1	41
unsure	9	1	1	11
favour no circumcision	3	2	8	13
<b>total</b>	<b>49</b>	<b>6</b>	<b>10</b>	<b>65</b>

### Participants' Responses to the Decisional Conflict Scale (DCS)

Parents' decisional conflict is detailed in Table 7. When the reliability of the decisional conflict scale was examined in this study, the alpha coefficient was 0.92. The total mean score for the DCS was 2.43 and 2.35 for the mothers and fathers, respectively. Among the subscales, parents expressed the greatest difficulty in feeling clear about values, followed by feeling informed, certain, and supported. About two thirds of the participants agreed or strongly agreed that they were certain about their choice. Over two thirds of them were aware of the options, but less than half stated they knew the advantages and less than half knew the disadvantages. Fewer than half of them felt clear about the personal importance of the pros and cons. Over two thirds of the parents had adequate support but less than half felt they had enough advice about the options.

**Table 7. Parents' responses to the decisional conflict scale (DCS).**

	FATHERS (n=63)		MOTHERS (n=86)	
	mean	SD	mean	SD
<b>Total DCS Score</b>	2.35	0.71	2.43	0.81
<b>Subscore categories</b>				
<b>Certainty</b>	2.15	1.11	2.2	1.12
	strongly agree/agree (%)		strongly agree/agree (%)	
easy choice	64%		68%	
sure what to do	71%		67%	
clear best choice	60%		67%	
<b>Informed</b>	2.52	1.09	2.56	1.07
aware of options	69%		72%	
know advantages	57%		51%	
know disadvantages	34%		41%	

<b>Clear Values</b>	<b>2.6</b>	<b>0.93</b>	<b>2.71</b>	<b>1.11</b>
	strongly agree/agree (%)		strongly agree/agree (%)	
clear about importance of advantages	59%		54%	
clear about importance of disadvantages	39%		43%	
clear about which is more important	54%		50%	
<b>Support</b>	<b>2.13</b>	<b>0.88</b>	<b>2.18</b>	<b>0.98</b>
	strongly agree/ agree(%)		strongly agree/agree (%)	
no pressure	88%		82%	
right amount of support	75%		66%	
enough advice	35%		48%	

When decisional conflict scores were analysed by stage of decision making and current opinion, there was a trend toward higher scores in the earlier stages and among the unsure, as shown in Table 8 below and Figure 5 and 6 (Appendix F).

**Table 8. Decisional Conflict by Stage of Decision Making and Current Opinion about Circumcision.**

Variable	Fathers			Mothers		
	n	mean	(95% CI)	n	mean	(95% CI)
<b>Stage of Decision Making</b>						
Stage 1 - not considering	9	2.5	(1.9, 3.1)	7	2.8	(2.2, 3.4)
Stage 2 - not considering but interested	7	3.0	(2.3, 3.7)	7	3.3	(3.1, 3.9)
Stage 3 - actively considering option	14	2.7	(2.4, 3.0)	18	3.2	(2.9, 3.5)
Stage 4 - close to selecting an option	4	2.7	(1.9, 3.5)	1	2.8	/
Stage 5 - have made a decision but will reconsider	6	2.5	(2.4, 3.0)	16	2.5	(2.2, 2.8)
Stage 6 - made a decision and will not change	21	1.7	(1.5, 2.0)	35	1.8	(1.6, 2.0)
<b>Opinion</b>						
favour circumcision	46	2.3	(2.2, 2.5)	50	2.3	(2.1, 2.5)
unsure	6	3.3	(2.6, 4.0)	15	3.2	(2.9, 3.5)
favour no circumcision	9	2.0	(1.4, 2.5)	20	2.2	(1.9, 2.6)

**Knowledge of Participants.** The percentages of the correct answers achieved by the parents are presented in Table 9. The alpha coefficient of the knowledge scale was 0.62. The mean scores achieved by mothers and fathers was 60.9 and 64.5 respectively. Almost all of mothers and fathers were accurately informed about the definition of circumcision and more than three quarters of them were aware of the current medical guidelines regarding routine neonatal circumcision. The majority of parents were knowledgeable about early versus late circumcision. Three quarters of fathers and half of the mothers were knowledgeable about cancer of the penis and circumcision status. The majority of the parents were aware that the circumcision procedure was painful. Half the fathers and as many mothers were knowledgeable about penile hygiene and circumcision status. Only a third of the participants were aware of the anatomy and physiology of the foreskin.

**Table 9. Parents' knowledge ( % correct answer)**

	FATHERS (n=65) knowledge total score mean 64.5 (SD 20.8)	MOTHERS (n=88) knowledge total score mean 60.9 (SD 21.4)
Variable	% correct	
Circumcision is removal of the foreskin.	99%	97%
If a baby is not circumcised as a newborn, he will not need to be circumcised in the future.	88%	81%
Professional guidelines state that routine circumcision is not medically indicated.	78%	78%
Circumcision does not prevent cancer of penis.	75%	67%
Circumcision procedure is painful	67%	60%
The foreskin protects penis.	65%	59%
Cleaning a baby who is not circumcised is easy.	57%	56%
Circumcision does not ensure proper hygiene.	51%	52%
The foreskin is necessary tissue.	38%	32%
The foreskin becomes retractable between the ages of 3 to 6 years of age	31%	33%

**Expectations.** Parents' expectation of problems with or without circumcision are described in Table 10 below and Figure 7 (Appendix F). About a quarter or less of the respondents had accurate expectations of outcomes. About one half stated they did not know the probabilities of outcomes. Among those providing estimates of probabilities, there was a tendency to overestimate the chances of acquiring a urinary tract infection and to underestimate the need for future circumcision and the complications of circumcision.

**Table 10.** Parents' expectation of problems

	FATHERS (n=67)				MOTHERS (n=88)			
<b>if infant is <u>not</u> circumcised</b>								
Variable	over-estimate	correct	under-estimate	don't know	over-estimate	correct	under-estimate	don't know
Acquiring a urinary tract infection	28.4%	10.4%	4.5%	56.7%	29.5%	10.2%	5.7%	54.5%
The need for future circumcision	9.2%	7.7%	38.5%	44.6%	9.2%	10.3%	32.2%	48.3%
<b>if infant is circumcised</b>								
Acquiring a urinary tract infection	31.3%	17.9%	1.5%	49.3%	32.9%	9.1%	2.3%	55.7%
Post operative complications	1.5%	26.8%	22.4%	49.3%	3.4%	25%	25%	46.6%
Complications requiring future surgery	0%	9%	38.8%	52.2%	0%	4.5%	39.8%	55.7%

**Values.** Parents' value scores are detailed in Table 11 on the next page and Figures 8 and 9 (Appendix F). Both mothers and fathers placed high importance on reducing the risk of infection and on avoiding surgical complications, such as penile injury and bleeding. Parents rated avoiding future circumcision and genital hygiene as moderately important to them. Mothers showed a higher mean value on the importance of pain (6.3) than fathers (4.8). The

least important factors affecting parents' decision were genital congruence, religious beliefs and cost.

**Table 11. Parents' value scores**

Reasons to circumcise				
	Fathers (n=67)		Mothers (n=88)	
Variable	mean	SD	mean	SD
reducing risk of infection	7.4	(2.7)	7.9	(2.5)
avoiding future circumcision	5.96	(3.6)	6.3	(2.9)
ease of cleaning	5.62	(3.5)	5.3	(3.7)
genital congruence	3.1	(3.8)	3.6	(3.8)
religious beliefs	1.98	(3.5)	1.69	(3.1)
Reasons not to circumcise				
	Fathers (n=67)		Mothers (n=88)	
Variable	mean	(SD)	mean	(SD)
penile injury	8.12	(2.5)	8	(2.7)
bleeding	6.42	(3.0)	7.5	(2.6)
pain	4.83	(3.5)	6.3	(3.4)
natural state	4.24	(3.4)	4.7	(3.5)
cost	1.87	(3.1)	1.9	(3.0)

Rating scale: 0=not at all important to me 10=extremely important to me

The responses about the most important reasons affecting parents' decisions are organized in Table 12. The most common themes in order of frequency were: infant well-being (15); outcomes (15); cleanliness (15); fitting in (15); and pain and discomfort (13). Other reasons affecting parents' decisions included: information (10); infection (10); decisional control (10); natural state (5); and sexuality (3).

Table 12. Parents' comments regarding the most important reason affecting their decision

Parental Quotes (n=115)		
<p><b>INFANT HEALTH (15)</b>            ...health of our baby            ...baby's long-term health            ...baby's well being now and later</p>	<p><b>OUTCOMES(15)</b>            ...doctor error, skill of physician            ...successful surgery ; proper surgery            ...complications ...avoiding future surgery            ...hospital standards            ...damage to his penis            ...long-term psychological problems</p> <p>"Is the medical need important?"</p> <p>"Is the surgery beneficial?"</p> <p>" Will I have to in the future by not doing it now?"</p>	<p><b>HYGIENE (15)</b>            ...clean like his father.            ...ease of cleaning            ...cleaning penis to ensure it is done properly.            ...circumcised penis easier to keep clean.</p> <p>"Circumcised men are cleaner."</p>
<p><b>PAIN (13)</b>            "Its barbaric!"            "Parents who want it should watch a video on circumcision."            ...not causing suffering to our baby.            ...avoiding pain and stress ...discomfort for the baby</p>	<p><b>INFORMATION (10)</b>            "What we have read is not enough to justify circumcising our son. His dad is not circumcised and he's not had any problems."            "I used to think it [circumcision] was supposed to happen. Now I know different."            "Who should decide? Parents or the doctor."</p>	<p><b>SEXUALITY (3)</b>            ...future sexuality            ...affecting sensitivity of penis            ...sexual knowledge of foreskin</p>
<p><b>FITTING IN (15)</b>            ...fitting in with society and what women prefer.            ...awkward around others            ...looks better ...not to make fun of in locker room</p> <p>"I want my son to feel he looks normal ie like other boys and men."</p> <p>"Everyone I know is circumcised."</p> <p>"I want him to look like his dad."</p>	<p>"The decision is too confusing;[sic] need someone else involved to help with advantages/disadvantages."</p>	<p><b>RELIGION/TRADITION (5)</b>            "Who cares if God told his followers to cut it [sic] off; he also told one [followers] to kill his son."            "I am Jewish."            ...Hindu - we have no knowledge of circumcision.            ...ancestral history            ...all the males in my family are circumcised.</p>
<p><b>INFECTION (10)</b>            ...STD protection</p> <p>"Circumcision decreases risk in getting STD and other diseases and infections by 20%."</p>	<p><b>NATURAL STATE (5)</b>            ...natural state/foreskin</p> <p>"I don't understand the need to remove healthy tissue."            "I just can't accept the notion that all males' anatomy is faulty at birth."            ...husband's experience as a non-circumcised male            ...men are born with it.</p>	<p><b>DECISIONAL CONTROL (10)</b>            ...agreement with spouse            ...what I feel and am comfortable with.            ...what other friends' experiences have been and male friends            ...husband wants circumcision            ...son's preferences when he is older            ...child to make decision when he is older.            ...personal preference            ...my son's opinion of our decision when he's older            "I will make the decision."            "We don't have enough information to make the decision yet."            "What I decide is right."</p>

**Preferred Role in Decision Making.** Parents' decisional preferences are outlined in Table 13. The majority of parents wanted to share the decision making with one another. In terms of decision making role with their physician, almost half of the group wanted to make the decision by themselves, while half of them preferred to make the decision after consulting with their doctor. One couple expressed a desire to consult with their priest.

**Table 13. Decision Making Style**

<b>Preferred Role (within family)</b>	<b>Fathers (n=67)</b>		<b>Mothers (n=88)</b>	
I prefer to make the decision myself	1	1.5%	2	2.3%
I prefer to share the decision with partner	65	97%	85	96.6%
Someone else should be involved	1	1.5%	1	1.1%
<b>Preferred Role (with physician)</b>				
I/We will decide on our own	30	44.8%	37	42%
I/We will decide after considering our doctor's opinion	34	50.7%	43	48.9%
I/We will decide with our doctor	2	3%	5	5.7%
My/Our doctor will decide after considering my/our opinion	0		0	
My/Our doctor will decide on his or her own	0		0	
Other	1	1.5%	3	3.4%

**Resources.** Parents' methods of receiving information are summarized in Table 14. Parents' preferences were varied with the most frequent sources being others' experience, followed by information materials and counselling from health professionals, mostly the family physician.

**Table 14. Parents' methods of receiving information about circumcision (n=151)**

	%
<b>TYPE</b>	
<b>Personal Choice</b>	
Others' Experience	50
<b>Information Materials</b>	
booklet	30
newspaper/magazine	26
Internet	23
video	5
<b>Personal counselling from health professional</b>	
family physician	20
obstetrician	9
prenatal instructor	9
midwife	3

**Prenatal Instructors' Survey**

**Sample.** Out of 25 instructors informed about the study, ten prenatal instructors consented voluntarily to participate. As shown in Table 15, the respondent's education and teaching experience varied widely. Most had a baccalaureate degree and at least one year's teaching experience. All the instructors used workshops or inservices as a method of continuing education.

**Table 15. Prenatal instructors' education, experience and resources (n=10)**

	<b>frequency</b>
<b>Education</b>	
RN diploma	10
BScN	8
MScN	2
Childbirth Educator	1
Lactation Consultant	1
<b>Teaching Experience</b>	
< 6 months	1
6 months to < 1 year	2
1-5 years	3
6-10 years	2
>10 years	
<b>Resources for Continuing Education</b>	
Workshops	10
Professional journals	9
Conferences	7
Magazines	7
Internet	5
Newspapers	4
Other	2
University courses	1

**Perception of the Decision.** All of the instructors surveyed stated that circumcision was discussed, usually in the class that dealt with newborn care. Seven of the instructors included the CPS statement regarding routine neonatal circumcision in their discussion. The content of their discussion included basic information about circumcision. The topics discussed are recorded according to their frequency as follows: the pros and cons (8); the procedure (6); CPS guidelines (6); the cost (3); the care of the circumcised or not circumcised penis (3); the pain of the procedure (3); the history of the practice (2); and various methods of circumcision (1).

Six out of ten of the instructors believed the decision to be difficult for parents, while the remainder (4) observed that most families had made a decision before coming to the class. The prenatal instructors who believed the decision to be difficult for parents, commented that “parents are not informed...”; “only aware of father’s experience”; “parents have many questions”; “...confusion whether it is the right thing to do”; “...uncertain about pain”; “conflicting information from family and friends...”.

The majority of the instructors (9/10) thought parents lacked information about harms and benefits and the chance of any problems. Four out of ten instructors believed parents to be unclear about the importance of the risks and benefits. In addition, some of the instructors stated that parents were not ready to make a decision, commenting that “some parents say ‘I hope it’s a girl then I won’t have to make the decision...’”. Five instructors commented that many parents experienced pressure regarding the decision either from other family members or friends or from their spouse.

The main advantages listed by the prenatal instructors, according to frequency included: cleanliness (4); none (3); decreased infection (2); religious and cultural preference (2); and genital appearance (1). The main disadvantages listed by the instructors, according to frequency were: pain (7); surgical risks (6); and exposure to unnecessary surgery (4).

Most instructors (8/10) stated that their usual role consisted of advice about the harms and benefits of either choice and encouragement for parents to make a personal decision. The majority of instructors (9/10) believed the partner to be most important in the decision. In addition, eight of the instructors thought the family doctor as well as family and friends played a significant role in the decision making process.

**Decision Support.** Prenatal instructors believed that there were several reasons that made decision support they provided, difficult. A few commented on their lack of teaching or personal experience with the decision. Some of difficulties were described as: (a) time constraints “...not enough time to deal with the issue effectively...”; (b) environment difficulties “...classes are not always easy to deal with every ones’ needs; (c) frustration “...personal inexperience and I don’t want parents to feel I support one [view] or the other ..., my personal preference..., parents who have no knowledge and base their decision on what friends did..., parents who have made up their mind”; and (d) scientific confusion “lack of medical consensus or need”. For other instructors decision support was not difficult because they stated, “I don’t get involved in the decision” or “it’s their decision”.

Other instructors believed group discussion made decision support easier by facilitating information dissemination. However, three instructors declined to comment and two believed the decision belonged to the parents.

**Resources.** Prenatal instructors preferred resources for parents’ decision support are listed in Table 16. Nine out of ten instructors preferred parents to receive personal counselling from a health practitioner and information material prepared by health societies. Group discussions were preferred by half. Seven of the instructors believed that parents get information on choices but only three of them believed that families consider the importance of the pros and cons of their choice. Only one instructor thought parents seek ways to handle pressure. The comments included; “most get support from family and friends...”; “if the doctor says he won’t do it, where can they go?” ; “they read magazines like ‘Great Expectations’”; and

“every class is different but in my class parents get detailed information and I share my bias’ with them”.

**Table 16**

**Prenatal instructors preferred resources for parents’ decision support (n=10)**

<b>Personal Counselling from</b>	<b>Frequency</b>
<b>Health practitioner</b>	
family physician	9
midwives	3
obstetrician	3
public health nurse	2
<b>Information material</b>	
booklets	9
Internet	6
video	3
CD-roms	1
<b>Source</b>	
societies	9
medical and health care specialists	8
government	6
pharmacies	3
consumer associations	1
<b>Discussion groups</b>	
prenatal classes	5

## Chapter Five

### Discussion

*This final chapter includes a discussion of the study findings organized according to the Decision Support Framework. The parent study is discussed first, followed by the prenatal instructors' survey. In addition, implications for future research and nursing as well as the study limitations are addressed.*

#### Parent Survey

##### Parents' Sample Characteristics

In the survey sample, the mothers' mean age was slightly higher (30.1) than the average age of 27.1 for the Ottawa-Carleton population of women giving birth in 1996 (Vital Statistics, 1996). In 1999, within the health department prenatal classes, 32% of the mothers were between the age of 26 to 30 years compared to the study sample of 45% in the same age category. Ninety one percent of the sample mothers were primiparas compared to 93% within the health department.

According to Statistics Canada, 33.7% of the population in the city of Ottawa, over 25 years of age have a university education (Education Statistics, Ottawa, Census '96). In this study, almost 75% of parents reported completion of university. This finding is comparable to Edwards' study (1994), in which the researcher noted that significant predictors of prenatal class attendance among primiparas, included maternal age and education.

##### Parents' Perception of the Decision

Parents expressed mild to moderate decisional conflict depending on their stage of decision making. The greatest difficulties occurred in "feeling uninformed" and "unclear

values”, particularly related to the knowledge and importance of the disadvantages of circumcision. These findings are consistent with the literature ( Enzenauer et al., 1986; Niku, Stock, & Kaplan, 1995; Tiemstra, 1999). Also consistent is the finding that parents who had reached a decision, had lower scores on the DCS, than those who were still deliberating. (O’Connor, 1995).

The main knowledge needs were related to the anatomy and physiology of the foreskin and circumcision as it relates to pain and hygiene. Three quarters of the fathers in this survey were circumcised, explaining the lack of knowledge about the foreskin. Only recently, the medical community has acknowledged the entity of infant pain in general and specifically during circumcision , therefore parents’ confusion about the significance of the pain is understandable.

There were significant deficits in parents’ expectations of the outcome of options. Most parents answered “don’t know” and very few parents were correct. In addition, some of them may have guessed at the answer. The medical literature describing outcomes related to circumcision, is unclear (Williams & Kapila, 1993). The tendency to overestimate benefits and underestimate risks has been reported in previous studies (Christensen-Szalanski et al., 1987; Maisels et al. 1983).

The dilemma in weighing the value of the benefits against the harms was illustrated in values scores where reducing the risk of infection was rated highly but so was avoiding penile injury and bleeding. For the participants in this study, few placed any relevance on religious beliefs or cost as a factor in promoting or not promoting circumcision. The majority of respondents was either protestant or Roman Catholic, denominations whose inclinations regarding circumcision are neutral (personal communication, Faculty of Canon Law, St Paul

University, Ottawa, Ont., Nov 12, 2000). Cost is a very subjective factor, therefore many parents desiring the procedure may overlook the financial burden perceiving the outcome to be justification for the expense. A majority of the participants expressed concerns about the risks of the procedure not only in the value score but in their comments, stating “doctor error...”; “successful surgery...”; “ damage to his penis”.

Close to a majority of parents had already made a decision, consistent with studies showing that choices are made early in pregnancy. The majority were leaning toward circumcision. These results should be considered in the context of the circumcision status of the group, where almost 75% of the fathers were circumcised.

#### Perception of Others

Virtually all participants wanted to include their partner in the decision and most believed that only the partner should be involved. For those who thought a physician should be involved, they saw the role as advisory. According to the DCS, the main support needs arose from lack of advice about options.

#### Resources

Parents used several resources for information. However, the most common source was others' experience and the least common was health professionals. The reliance of parents on others' experience reflects the strong social and cultural basis for circumcision. Again these results are consistent with others' findings (Maisels, 1983; Stein et al. 1982; Tiemstra, 1999).

#### Prenatal Instructors Survey

Although all the instructors stated that circumcision was discussed, the content of the discussion varied according to the instructor's experience and perception of the decision. Most

of the instructors conveyed the CPS guidelines which is congruent with parents' knowledge regarding the routine practice of newborn circumcision.

Over half of the instructors believed the decision to be difficult for parents while a couple of instructors with many years of teaching experience thought the decision was not difficult stating that "most have made up their minds before class... parents have definite ideas... regardless of medical info'...". Perhaps these instructors' perception of the decision has more to do with their frustration of conveying information that is not acknowledged. Most instructors believed parents lacked both information and chances of the benefits and harms of their choice. Other studies have confirmed these findings (Christian-Salanski et al., 1987; Brown & Brown, 1987; Walton et al. 1997).

Only a few of the instructors believed circumcision to have no advantages while others commented on the possible benefits from decreased infection, improved cleanliness and a more desirable appearance. Most instructors regarded the procedure as unnecessary and painful. The findings from the study may reflect the instructors' personal bias towards the decision and their confusion about the benefits.

The majority of the instructors saw their role as a counsellor or advisor and most of them attempted a neutral tone in their discussions. One instructor stated that she shared her bias with them. Tiemstra (1999) noted that parents' opinion about circumcision, after receiving a provider's discussion that was neutral in tone, remained unchanged.

All the instructors believed the partner was significant in the decision, followed by the physician, family and friends. Few of them saw their role as instrumental in the decision. Collectively, the factors that impacted negatively on decision support were related to inadequate

teaching experience; time constraints; lack of medical consensus in the literature; frustration with the topic; and personal bias. Many instructors agreed that improved counselling techniques and current information about circumcision were key factors in improving decision support. The instructors' perception of the decision was consistent with the parents' views, commenting on the need for current information, clarification of values and the probability of outcomes.

### Resources

Prenatal instructors lacked consensus on where parents get information. However, the instructors believed reliable sources for circumcision information would be the family doctor, booklets; health societies; and government agencies. One nurse wrote on her questionnaire... "Should this practice be seen [more] as a cultural preference [than] and not a medical issue?" This view is supported by the parents' reliance on the experiences of others who were not health professionals.

### Limitations of the Study

The limitations of this study are primarily problems of design and generalizability. The survey design captured parents' views from one geographic location. Therefore, the views in the greater population have not been assessed. Parents in these prenatal classes were well educated and slightly older than average. Surveying younger, less educated parents may yield very different decision making needs. For reasons of expediting the study, a convenience sample of prenatal instructors were chosen as key informants. However, in clinical practice other practitioners are involved in providing decision support (obstetricians; family physicians). Another limitation may be the timing of the survey. Studies have shown that many parents have an opinion about circumcision before becoming pregnant.

### **Implications for Future Research**

The needs assessment could be expanded to include parents who are younger and less educated. Moreover, other health professionals such as urologists, paediatricians, neonatologists and family doctors might yield other information about decision making and circumcision.

The current study was developed as a needs assessment, to direct the provision of decision support in prenatal classes. A next step would be to develop and evaluate interventions to improve the sub-optimal components of the DSF. For example interventions would need to be developed to increase parents' knowledge of the options; clarify parents' values regarding the importance of outcomes (particularly disadvantages); and facilitate access to support (particularly advice).

### **Implications for Nursing**

Nurses are in a key position to support families, regarding the circumcision decision. By organizing the circumcision decision according to the DSF, prenatal instructors can not only improve parents' perception of the decision, but they are better able to identify the specific factors contributing to parents' decisional conflict. In this study, parents lacked awareness of the options and the potential outcomes of their choice. Instructors can improve parents' knowledge about the anatomy and physiology of the foreskin and the probability of infection and future circumcision. If parents choose circumcision, nurses can inform them of the necessity for and efficacy of analgesia. Decision support either through a structured decision aid or personal counselling is important, ensuring that parents enter into the decision fully informed. Nurses can foster improved decision making, by understanding the complexity of the decision and recognizing opportunities to provide skilled decision support.

Through the consultative and educative roles, nurses in advanced practice can facilitate decision support for parents through other health care providers. Through the research role, advanced practice nurses can develop and evaluate interventions that can be used in clinical settings, decreasing myths and misconceptions about circumcision and thereby increasing satisfaction with the decision from the perspective of both practitioner and parent alike.

### Conclusions

Despite the limitations, this study is an important first step in assessing parents' and prenatal instructors' needs regarding circumcision organized in a conceptual framework. By framing the circumcision decision in this fashion, the determinants of the decision are elucidated, and the sub-optimal determinants identified. The use of the framework allows health care professionals to better understand the choice dilemma of their clients and ultimately to become more effective in decision support.

In closing, parents appear to have knowledge deficits, some decisional conflict, and unclear values. The study has shown that parents are very interested in decision making and desire to make the most informed decision for themselves and their child.

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## Appendices

### Appendix A - Sample size calculations

## Appendix A

Sample size calculation: Gower and Kelly (1988).

1. Initial sample size:

$$n^1 = \frac{z^2 pq}{d^2}$$

where  $z = 1.96$  for a 95% confidence interval  
 $p =$  a preliminary estimate of the proportion of the population having the characteristics of interest; conservative estimate of variability is set at 0.50  
 $q = 1-p$   
 $d =$  the specified margin of error, set at +/- 0.10

therefore  $n^1 = \frac{(1.96)^2 (0.50)(0.50)}{(0.10)^2}$

$$n^1 = \frac{(3.8416)(.25)}{.01}$$

$$n^1 = \frac{9604}{.01} = 96.04$$

2. Initial sample size adjusted for the population size using:

$$n^2 = n^1 \frac{N}{N + n^1}$$

$N = 1100$  size of the survey population

$$n^2 = 96.04 \left( \frac{1100}{1100 + 96.04} \right)$$

$$n^2 = 88^* (100\% \text{ response})$$

3. Non-response:  $r =$  expected response rate = 75% (high with no incentive)

$$n = \frac{n^2}{r} \quad 88/.75$$

$$n^3 = 118 \text{ or } 177 \text{ if response}(r) \text{ is } .50$$

**Appendix B**

**Appendix B Parent Questionnaire**

Date: \_\_\_\_\_

ID: \_\_\_\_\_

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**PARENTS' OPINION SURVEY**

**ABOUT**

**NEONATAL**

**MALE CIRCUMCISION**

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**I realize by completing this questionnaire, I am giving my informed consent to participate.  yes**

---

### **A. My Stage of Decision Making**

We would like to know how much you have been thinking about the circumcision decision. Please check [✓] in the box that best reflects where you are in your decision making.

At this time, would you say you:

- haven't begun to think about choices;
- haven't begun to think about the choices, but are interested in doing so;
- are considering the options now;
- are close to selecting an option
- have already made a decision, but are still willing to reconsider;
- have already made a decision and are unlikely to change your mind

### **B. My opinion about circumcising my son**

We want to know your opinion about circumcision at this moment.

If your doctor or midwife asked you **right now** to make a decision about circumcising your infant, please show where you would be on the scale below, by placing a check in the box [✓].

If you want your son circumcised, you would check [✓] far to the left.

If you did not want your son circumcised you would check [✓] far to the right.

If you are unsure, you would check [✓] in the middle.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
<b>yes</b>	<b>unsure</b>						<b>no</b>				<b>circumcision</b>				
<b>circumcision</b>												<b>circumcision</b>			

### C. My difficulty making this choice

Now, thinking about your opinion at this moment, please look at the following comments made by some parents when deciding about neonatal circumcision for their son.

Please show how strongly you agree or disagree with these statements by **circling** the number from 1 ( **strongly agree**) to 5 (**strongly disagree**) which best shows how you feel about the choice you just made.

---

This decision is <b>easy</b> for me to make	1 strongly agree	2 agree	3 neither agree nor disagree	4 disagree	5 strongly disagree
I'm sure what to do in this decision	1 strongly agree	2 agree	3 neither agree nor disagree	4 disagree	5 strongly disagree
It's clear what choice is best for me and my son	1 strongly agree	2 agree	3 neither agree nor disagree	4 disagree	5 strongly disagree
I am aware of the options I have in this decision	1 strongly agree	2 agree	3 neither agree nor disagree	4 disagree	5 strongly disagree
I feel I know the <b>advantages</b> of neonatal circumcision	1 strongly agree	2 agree	3 neither agree nor disagree	4 disagree	5 strongly disagree
I feel I know the <b>risks and disadvantages</b> of neonatal circumcision	1 strongly agree	2 agree	3 neither agree nor disagree	4 disagree	5 strongly disagree

<b>I am clear about how important the advantages are to me and my son in this decision</b>	<b>1 strongly agree</b>	<b>2 agree</b>	<b>3 neither agree nor disagree</b>	<b>4 disagree</b>	<b>5 strongly disagree</b>
<b>I am clear about how important the risks and disadvantages are to me and my son in this decision</b>	<b>1 strongly agree</b>	<b>2 agree</b>	<b>3 neither agree nor disagree</b>	<b>4 disagree</b>	<b>5 strongly disagree</b>
<b>I am clear about which is more important for me and my son (the advantages or the disadvantages)</b>	<b>1 strongly agree</b>	<b>2 agree</b>	<b>3 neither agree nor disagree</b>	<b>4 disagree</b>	<b>5 strongly disagree</b>
<b>I am making this choice without any pressure from others</b>	<b>1 strongly agree</b>	<b>2 agree</b>	<b>3 neither agree nor disagree</b>	<b>4 disagree</b>	<b>5 strongly disagree</b>
<b>I have the right amount of support from others in making this choice</b>	<b>1 strongly agree</b>	<b>2 agree</b>	<b>3 neither agree nor disagree</b>	<b>4 disagree</b>	<b>5 strongly disagree</b>
<b>I have enough advice about the options</b>	<b>1 strongly agree</b>	<b>2 agree</b>	<b>3 neither agree nor disagree</b>	<b>4 disagree</b>	<b>5 strongly disagree</b>

### **D. My role in decision making about my son's circumcision**

Some parents want to make the decision about their son's circumcision on their own. Others prefer to share the decision with their partner or doctor. Still others prefer to leave the final decision to their partner or doctor.

1. Within your family, who should be involved in making the decision? Please check  one:

- I prefer to make the decision myself, using all I know or learn about circumcision.
- I prefer that my partner and I share the decision together, on an equal basis
- I prefer that my partner make the decision
- Someone else should be involved in making the decision, [*specify*] \_\_\_\_\_

2. Which of the following statements best describes how the decision will be made. Please check  one:

- I/we will decide on my/our own
- I/We will decide, after considering my/our doctor's opinion
- I/We will decide with our doctor, on an equal basis
- My/Our doctor will decide, after considering my/our opinion
- My/Our doctor will decide on his or her own
- Other [*specify*] \_\_\_\_\_
- Don't know

### E. What I know about circumcision now

We would like to know how familiar you are about the practice of circumcision in male infants. Below are listed some statements about circumcision. Please show whether you think they are true, false or you are not sure by checking [ ✓ ] ONE box beside each statement.

- 
- |  |                               |                                |                                 |
|--|-------------------------------|--------------------------------|---------------------------------|
| 1. Circumcision is the <b>removal</b> of the foreskin.   | <input type="checkbox"/> True | <input type="checkbox"/> False | <input type="checkbox"/> Unsure |
| 2. The foreskin is <b>unnecessary</b> tissue.  | <input type="checkbox"/> True | <input type="checkbox"/> False | <input type="checkbox"/> Unsure |
| 3. The foreskin <b>protects</b> the glans (head) of the penis.   | <input type="checkbox"/> True | <input type="checkbox"/> False | <input type="checkbox"/> Unsure |
| 4. On average, the foreskin naturally becomes <b>retractable</b> (moveable) between 3 to 6 years of age.         | <input type="checkbox"/> True | <input type="checkbox"/> False | <input type="checkbox"/> Unsure |
| 5. Professional guidelines state that circumcision is <b>medically necessary</b> .                               | <input type="checkbox"/> True | <input type="checkbox"/> False | <input type="checkbox"/> Unsure |
| 6. Circumcision ensures <b>proper</b> (penis) hygiene.   | <input type="checkbox"/> True | <input type="checkbox"/> False | <input type="checkbox"/> Unsure |
| 7. Circumcision is a <b>painful</b> procedure.   | <input type="checkbox"/> True | <input type="checkbox"/> False | <input type="checkbox"/> Unsure |
| 8. Cleaning a penis that is <u>not circumcised</u> , is <b>difficult</b> .                                       | <input type="checkbox"/> True | <input type="checkbox"/> False | <input type="checkbox"/> Unsure |
| 9. If a baby is <u>not circumcised</u> as a newborn, he will likely <b>need to be circumcised</b> in the future. | <input type="checkbox"/> True | <input type="checkbox"/> False | <input type="checkbox"/> Unsure |
| 10. Circumcision <b>prevents</b> cancer of the penis.  | <input type="checkbox"/> True | <input type="checkbox"/> False | <input type="checkbox"/> Unsure |

**F. A baby's chances of problems if he is not circumcised.**

We are interested in your opinion about a baby's chances of problems if he is not circumcised.

**Urinary Tract Infections**

1. Out of **1000 infant boys** who are not circumcised, how many will have a urinary tract infection in the first year of life? Please check [✓] one :

- Don't know**
- All:** 1000 out of 1000 infant boys will have a urinary tract infection in the first year.
- Most:** 750 -999 out of 1000 infant boys will have a urinary tract infection in the first year.
- The Majority:** 501-749 infant boys out of 1000 will have a urinary tract infection in the first year.
- Many:** 251-500 infant boys out of 1000 will have a urinary tract infection in the first year.
- Several:** 101-250 infant boys out of 1000 will have a urinary tract infection in the first year.
- Some:** 61-100 infant boys out of 1000 will have a urinary tract infection in the first year.
- Few:** 20-60 infant boys out of 1000 will have a urinary tract infection in the first year
- Very Few:** 7-19 infant boys out of 1000 will have a urinary tract infection in the first year.
- Next to None:** 1-6 infant boys out of 1000 will have a urinary tract infection in the first year.
- None:** 0 infant boys out of 1000 will have a urinary tract infection in the first year.

**Need for future surgery**

2. Out of **1000 infant boys** who are not circumcised, how many will have a medical need to be circumcised in the future? Please check [✓] one :

- Don't know**
- All:**                    **1000** out of **1000** infant boys will have to be circumcised in the future.
- Most:**                    **750 -999** out of **1000** infant boys will have to be circumcised in the future.
- The Majority:**    **501-749** infant boys out of **1000** will have to be circumcised in the future.
- Many:**                    **251-500** infant boys out of **1000** will have to be circumcised in the future.
- Several:**                **101-250** infant boys out of **1000** will have to be circumcised in the future.
- Some:**                    **61-100** infant boys out of **1000** will have to be circumcised in the future.
- Few:**                     **20-60** infant boys out of **1000** will have to be circumcised in the future.
- Very Few:**              **7-19** infant boys out of **1000** will have to be circumcised in the future.
- Next to None:**        **1-6** infant boys out of **1000** will have to be circumcised in the future
- None:**                    **0** infant boys out of **1000** will have to be circumcised in the future.

## **G. A baby's chances of having any problems or complications if he is circumcised**

### **Urinary tract infections**

We are interested in your opinion about a baby's chance of a urinary tract infection if he is circumcised.

1. Out of 1000 infant boys who are circumcised, how many will have a urinary tract infection in the first year of life? Please check [✓] one:

- Don't know**
- All:** 1000 out of 1000 infant boys will have a urinary tract infection in the first year.
- Most:** 750 -999 out of 1000 infant boys will have a urinary tract infection in the first year.
- The Majority:** 501-749 infant boys out of 1000 will have a urinary tract infection in the first year.
- Many:** 251-500 infant boys out of 1000 will have a urinary tract infection in the first year.
- Several:** 101-250 infant boys out of 1000 will have a urinary tract infection in the first year.
- Some:** 61-100 infant boys out of 1000 will have a urinary tract infection in the first year.
- Few:** 20-60 infant boys out of 1000 will have a urinary tract infection in the first year.
- Very Few:** 7-19 infant boys out of 1000 will have a urinary tract infection in the first year.
- Next to None:** 1-6 infant boys out of 1000 will have a urinary tract infection in the first year.
- None:** 0 infant boys out of 1000 will have a urinary tract infection in the first year.

### **Immediate Complications: Infections, bleeding, or penile injury**

We are interested in your opinion about a baby's chances of having problems soon after surgery such as infection, bleeding or penile injury (damage to the head of his penis), if he is circumcised.

2. Out of **1000 infant boys who are circumcised**, how many will have complications soon after surgery? Please check [✓] one :

**Don't know**

**All:** **1000** out of **1000** infant boys will have complications immediately following a circumcision?

**Most:** **750-999** out of **1000** infant boys will have complications immediately following a circumcision?

**The Majority:** **501-749** infant boys out of **1000** will have complications immediately following a circumcision?

**Many:** **251-500** infant boys out of **1000** will have complications immediately following a circumcision?

**Several:** **101-250** infant boys out of **1000** will have complications immediately following a circumcision?

**Some:** **61-100** infant boys out of **1000** will have complications immediately following a circumcision?

**Few:** **20-60** infant boys out of **1000** will have complications immediately following a circumcision?

**Very Few:** **7-19** infant boys out of **1000** will have complications immediately following a circumcision?

**Next to None:** **1-6** infant boys out of **1000** will have complications immediately following a circumcision?

**None:** **0** infant boys out of **1000** will have complications immediately following a circumcision?

**Later complications: poor cosmetic results or narrowed urinary opening**

We are interested in your opinion about a baby's chances of having any problems later on such as poor cosmetic results or a narrowed urinary opening, requiring additional surgery, if he is circumcised.

3. Out of 1000 infant boys who are circumcised, how many will have future complications such as poor cosmetic results or a narrowed urinary opening, following a circumcision?  
Please check [✓] one :

- Don't know**
- All:** 1000 out of 1000 infant boys will have future complications following a circumcision?
- Most:** 750-999 out of 1000 infant boys will have future complications following a circumcision?
- The Majority:** 501-749 infant boys out of 1000 will have future complications following a circumcision?
- Many:** 251-500 infant boys out of 1000 will have future complications following a circumcision?
- Several:** 101-250 infant boys out of 1000 will have future complications following a circumcision?
- Some:** 61-100 infant boys out of 1000 will have future complications following a circumcision?
- Few:** 20-60 infant boys out of 1000 will have future complications following a circumcision?
- Very Few:** 7-19 infant boys out of 1000 will have future complications following a circumcision?
- Next to None:** 1-6 infant boys out of 1000 will have future complications following a circumcision?
- None:** 0 infant boys out of 1000 will have future complications following a circumcision?







## **I. Helping me make an informed decision**

There are many ways to learn more about available options when you are making a difficult decision. Which of the following sources of information have you already used? Please check  all that apply:

- information in a booklet
- discussion with my family doctor
- discussion with my obstetrician
- discussion with my midwife
- discussion with my prenatal instructor
- video on the procedure
- information about others' experiences
- information from the Internet
- information in a magazine / newspaper
- other (*specify*) \_\_\_\_\_

### **Background Information**

1. Are you:       female  
                     male
  
2. What is your age: \_\_\_\_\_ years.
  
3. What is the highest grade or level of education you have completed? Check ( ✓ ) one.
  - less than grade 9
  - some high school
  - high school diploma
  - trade school certificate/diploma
  - some college
  - college diploma/degree
  - some university
  - university degree
  - refused
  
4. What religious affiliation do you have? \_\_\_\_\_
  
5. How many weeks pregnant are you/your partner? \_\_\_\_\_ weeks
  
6. Is this your/your partner's first pregnancy?    yes    no
  
7. Do you know the sex of your unborn baby?    yes    no  
 If you know the sex of this baby: It is:         girl    boy
  
8. How many children do you have? \_\_\_\_\_
  
9. How many of your children are boys? \_\_\_\_\_
  
10. Are your male children circumcised?  
 yes - all of them     yes - some of them     no - none     n/a
  
11. Is the baby's father circumcised?     yes     no     not sure
  
12. What language is spoken most at home? Check ( ✓ ) one.  
 English     French     Other (specify) \_\_\_\_\_

**Thank you for participating in this study. The information you have shared with us is important and we appreciate the time you have taken to answer the questions.**

**RESOURCES:**

For parents wishing additional information about circumcision, please contact the Canadian Pediatric Society for a copy of the article, *Neonatal Circumcision Revisited*.

The article can be accessed from the Internet or by fax.

**Canadian Pediatric Society - [www.CPS.ca](http://www.CPS.ca)**

**100-2204 Walkley Rd**

**Specific questions about circumcision should be discussed with your health care practitioner.**

**Appendix C**

**Appendix C Prenatal Instructors Questionnaire**

**Needs Assessment Questionnaire  
Personal Interview Questions for Prenatal Instructors**

My name is Susan Taylor Clapp of the University of Ottawa and I am interested in learning about your role in supporting parents in their decision making regarding neonatal male circumcision. This information will contribute to a better understanding of the decision making needs of parents and improve our planning of decision support. The information you share during this interview will be kept confidential. The interview will only take 30 minutes.

**PERCEPTION OF THE DECISION**

1. Do you discuss circumcision in your prenatal class?

yes  no

2. Explain what is discussed.

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3. Do parents find this a difficult decision to make?

yes  no

Explain:

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4. What makes the decision difficult for parents? Please check [ ✓ ] all that apply.

- Are parents lacking information about options - advantages and risks
- Are parents lacking information on the chances of disadvantages and risks
- Are parents unclear about what is important
- Are parents lacking information on what others decide
- Are parents feeling pressure from others
- Are parents lacking the skill or ability to make this type of decision
- Are parents lacking motivation or not feeling ready to make the decision

5. What do you see as the main advantages of circumcision?

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6. What do you see as the main disadvantages of circumcision?

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7. What is your usual role in making this decision? Please check [✓] all that apply.

- I advise parents about the advantages and disadvantages of circumcision.
- I advise parents about the advantages and disadvantages of not being circumcised.
- I encourage parents to make the decision on their own.
- I don't get involved in the decision; it is a personal decision.
- Other [*specify*] \_\_\_\_\_

8. Who else is usually involved in the decision? Please check [✓] all that apply.

- partner
- obstetrician
- family doctor
- midwife
- prenatal instructor
- delivery room nurse
- post partum nurse
- relatives
- friends

9. What factors make it difficult for you to support the parents' decision making ?

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10. What factors make it easier for you to support the parents decision making?

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## RESOURCES

1. How do parents usually go about making this decision? Please check [✓] all that apply.

Do they:  get information on choices

get information on how likely the choices are

consider how important the choices are

get information on how others decide or recommend

find ways to handle pressure

get support from others

other (*specify*) \_\_\_\_\_

2. I will list possible ways to help some parents with this decision. Which ones do you think may be useful to parents? Please check [✓] all that apply.

Counselling from health practitioner; If YES, what types of practitioner?  
\_\_\_\_\_

Discussion groups of parents facing the same decision. IF YES, what type of organization or group \_\_\_\_\_

Information materials; If YES, please circle the type of medium.

booklets, pamphlets

videos

CD ROMS

Internet

other, (specify) \_\_\_\_\_

3. Who do you think should prepare information about the decision? Please check [✓] all that apply.

- pharmacies
- health societies (Canadian Pediatric Society, Society of Obstetricians & Gynecologist)
- expert medical and health practitioners
- government (Health Canada - guidelines)
- consumer associations
- insurance companies
- private companies that produce and sell drugs and health products

4. Is there anything else that would help you to do a better job supporting your parents' decision making?

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## CHARACTERISTICS OF THE PRACTITIONER

1. How many years have you taught prenatal classes? \_\_\_\_\_ years
2. Have you taken additional courses beyond a baccalaureate degree?  yes  no  
Please [✓] all that apply:
  - Lactation Consultant
  - Child Birth Educator
  - Master's Degree
  - Other (specify) \_\_\_\_\_
3. How do you keep your knowledge up to date within the prenatal program?  
Please [✓] all that apply:
  - Professional Journals
  - Work Shops
  - Internet
  - University courses
  - Conferences
  - Newspaper
  - Magazines
  - Other (specify) \_\_\_\_\_
4. Do you feel confident about your knowledge of the advantages and disadvantages of both  
circumcising and not circumcising a male infant?  yes  no
5. If no, what would help?

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Thank you for taking the time to answer these questions.

**Appendix D**

**Appendix D Prenatal Instructors' Consent**

**Loeb Health Research Institute  
&  
University of Ottawa**

**Prenatal Instructors Consent Form**

**Nature of the Study:** The information you share in the interview will be used to determine the decision support needs of families considering circumcision for their son. The information gathered from this research may be used to develop educational material that may be used in clinical practice, helping parents make an informed decision regarding neonatal male circumcision.

**Researchers:** Susan Taylor Clapp, RN MScN(C)  
Annette O'Connor, RN PhD  
University of Ottawa, School of Nursing and Loeb Health Research Institute

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In signing this document, I am giving my consent to be interviewed as part of a study conducted by Susan Taylor Clapp, the University of Ottawa and the Clinical Epidemiology Unit, Loeb Health Research Institute.

1. I understand that I will be asked to share my views about circumcision and decision making.
2. I understand that I will be interviewed in a place and time that is convenient to me. The questionnaire will take about 15 minutes to complete.
3. I understand that I have the right to refuse to participate in the survey without affecting my status in the Health Department. My answers to the questions will be completely confidential and no one will be able to link my name to my answers. My name will not be recorded with my responses or identified in any way in future publications.
4. I understand that participation is voluntary. I may choose to withdraw at any time and refuse to answer any specific questions.
5. I understand that the results of this study will be given to me if I wish.

If I have concerns or questions about the study or the interview, I may contact:  
Susan Taylor Clapp at 830 6171.

I acknowledge receipt of a copy of this consent form.

Participant: \_\_\_\_\_ Date: \_\_\_\_\_

Witness: \_\_\_\_\_

**Research Summary:**

I would like to receive a summary of the final study results.  yes  no

Mail to: \_\_\_\_\_

**Appendix E**

**Appendix E Pilot Study Questionnaire**

**PILOT STUDY****PARENT'S OPINION SURVEY ABOUT NEONATAL MALE  
CIRCUMCISION**

**We are interested in your comments about this study.**

**6. How long did this questionnaire take to finish? \_\_\_\_\_ minutes**

**7. Did you find any of the questions hard to understand?  yes  no**

**If your answer is yes, please specify: \_\_\_\_\_**

\_\_\_\_\_

**3a. Did you find any of the questions upsetting?  yes  no**

**If your answer is yes, please specify: \_\_\_\_\_**

\_\_\_\_\_

**3b. What would have helped you deal with your upset?**

\_\_\_\_\_

**Thank you for your participation.**

## Appendix F

### Additional Figures Describing Results

**Figure 4. Choice predisposition**

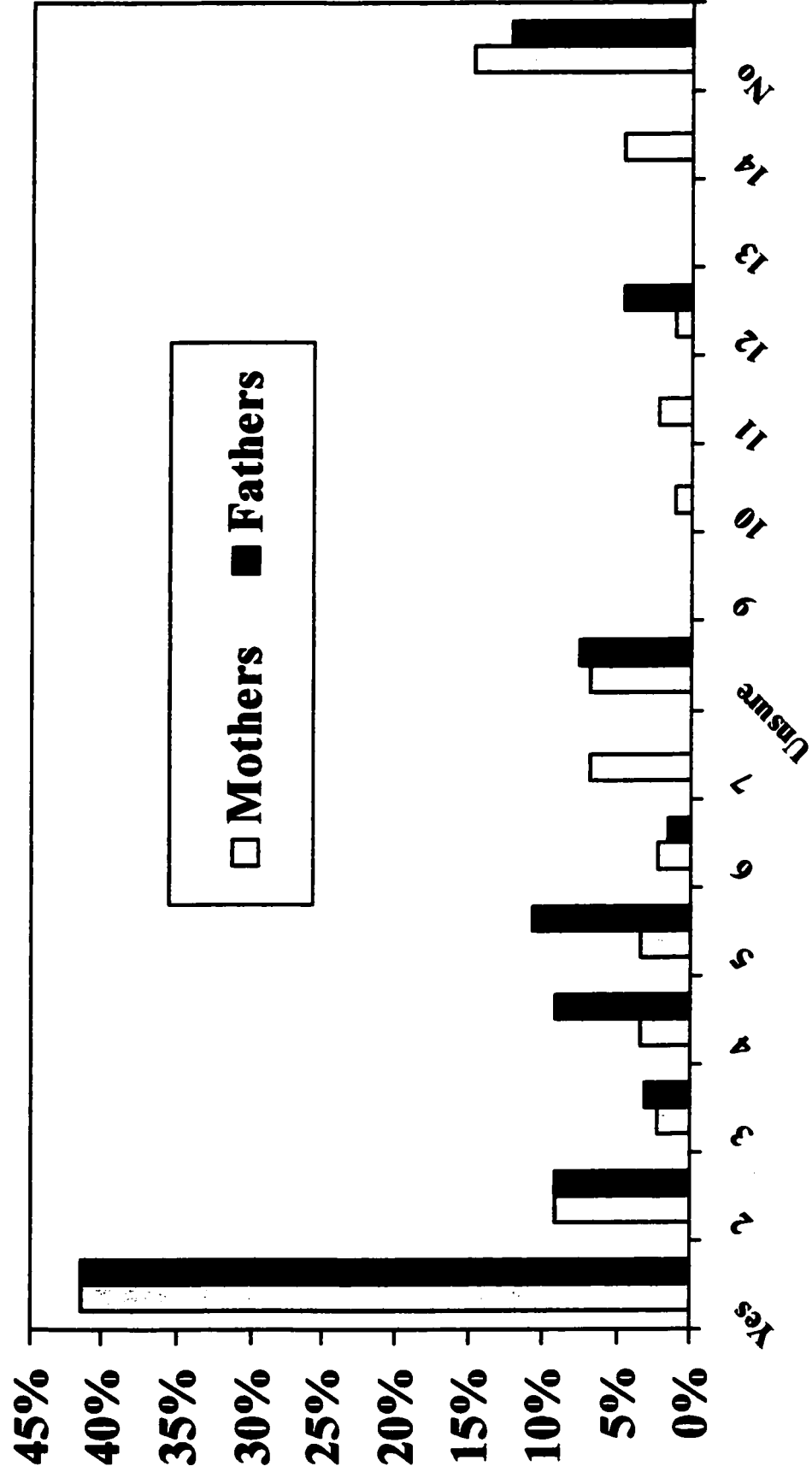
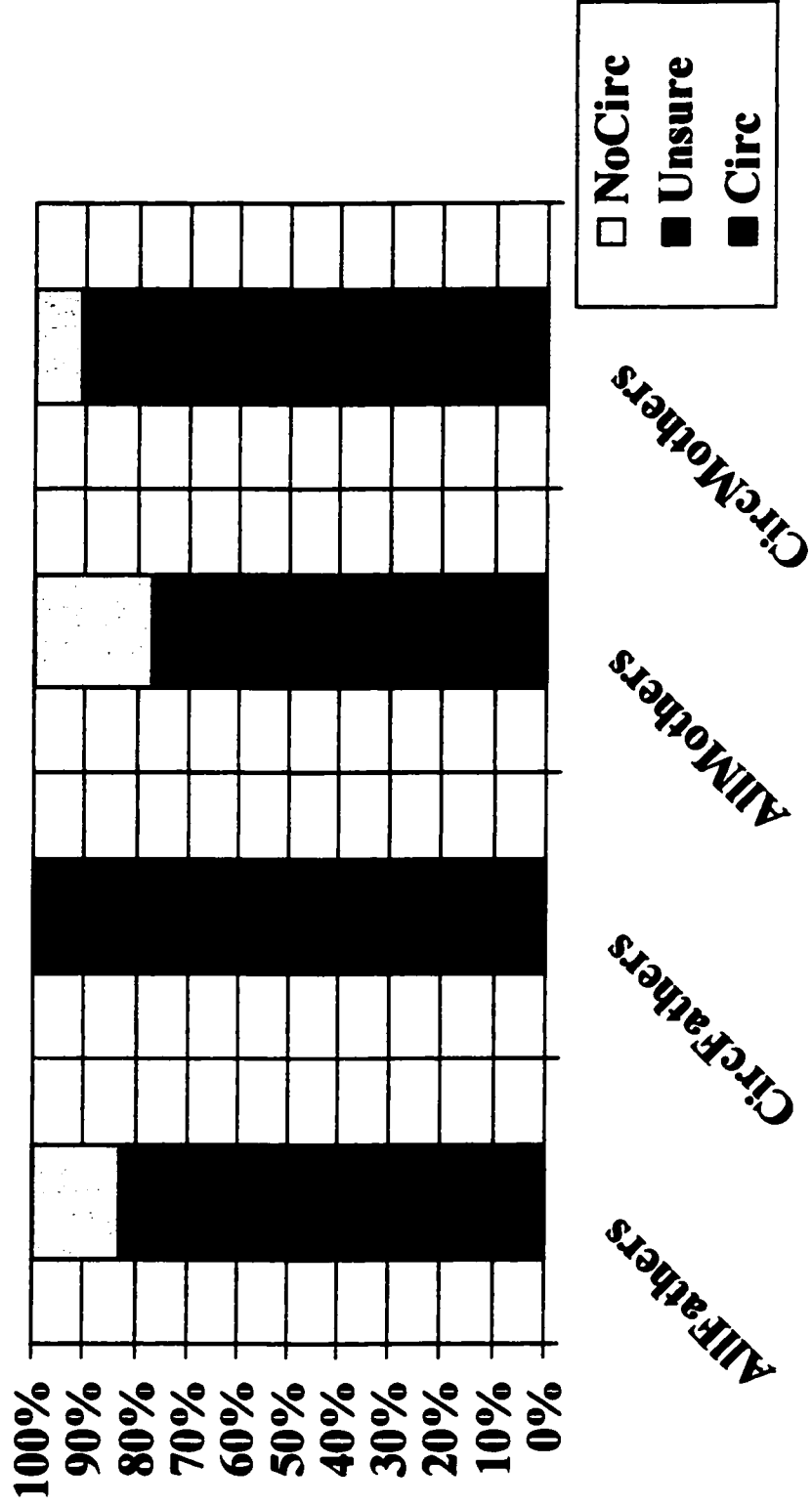
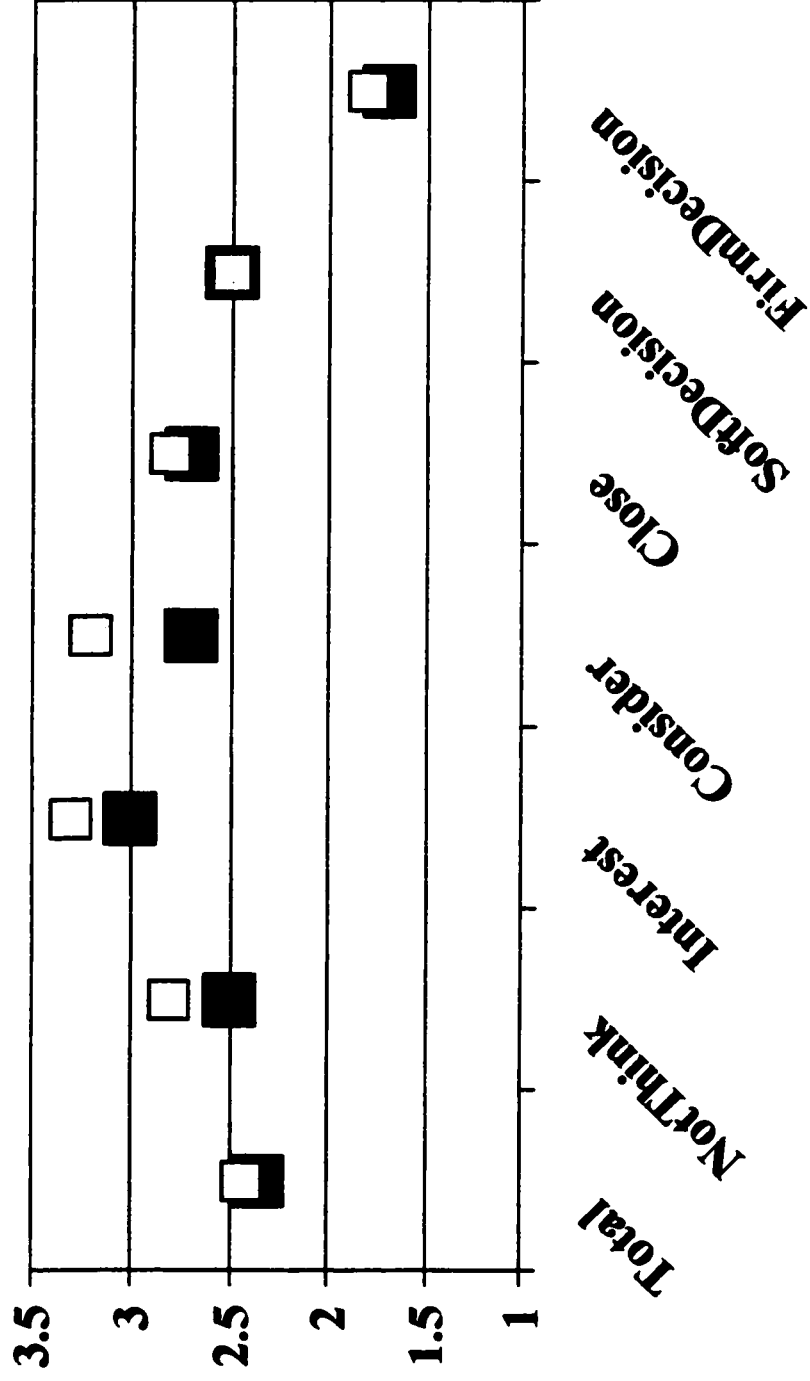


Figure 5. Parents' current opinion about circumcision



**Figure 6. Decisional Conflict by Stage of Decision Making**



**Figure 7.**  
**Decisional Conflict by Predisposition Toward Options**

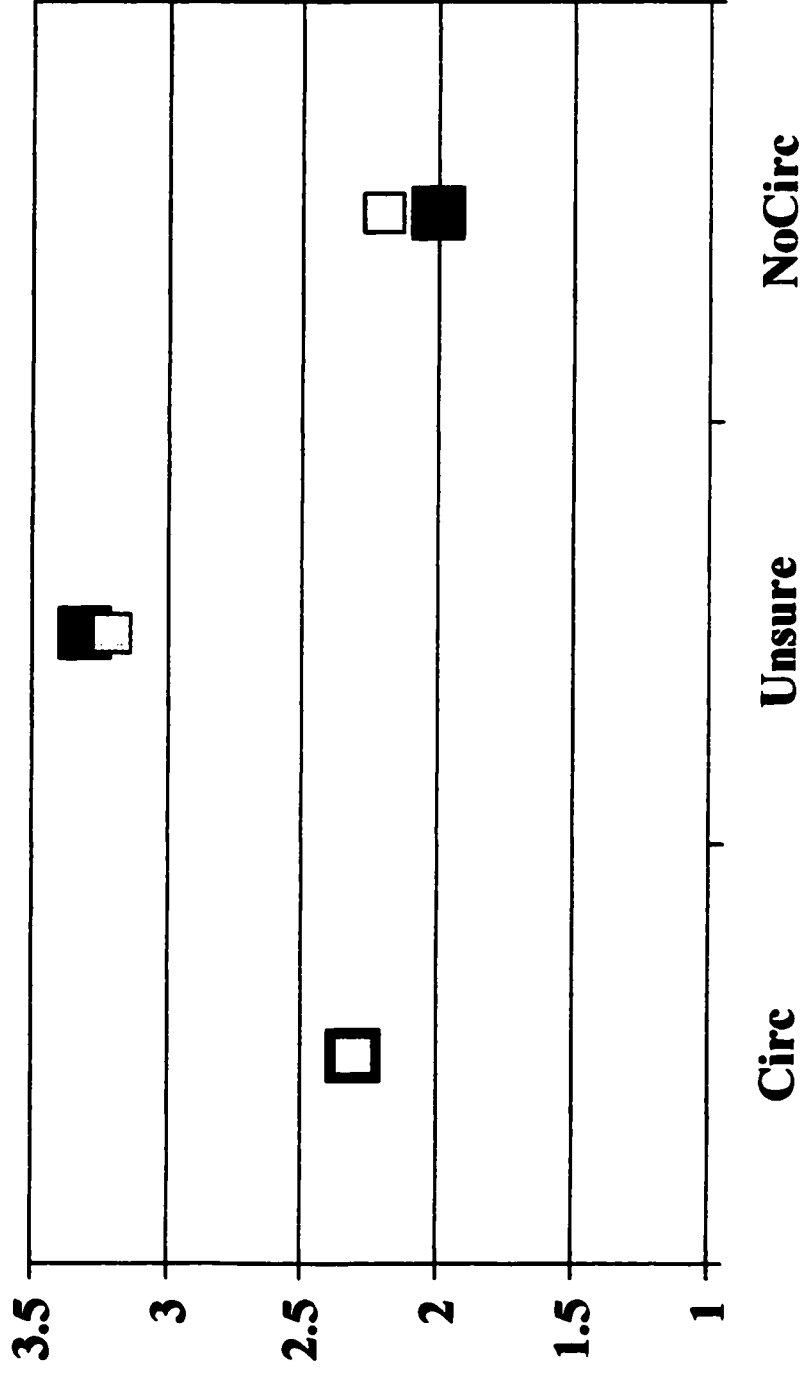


Figure 8. Expectations of Outcomes

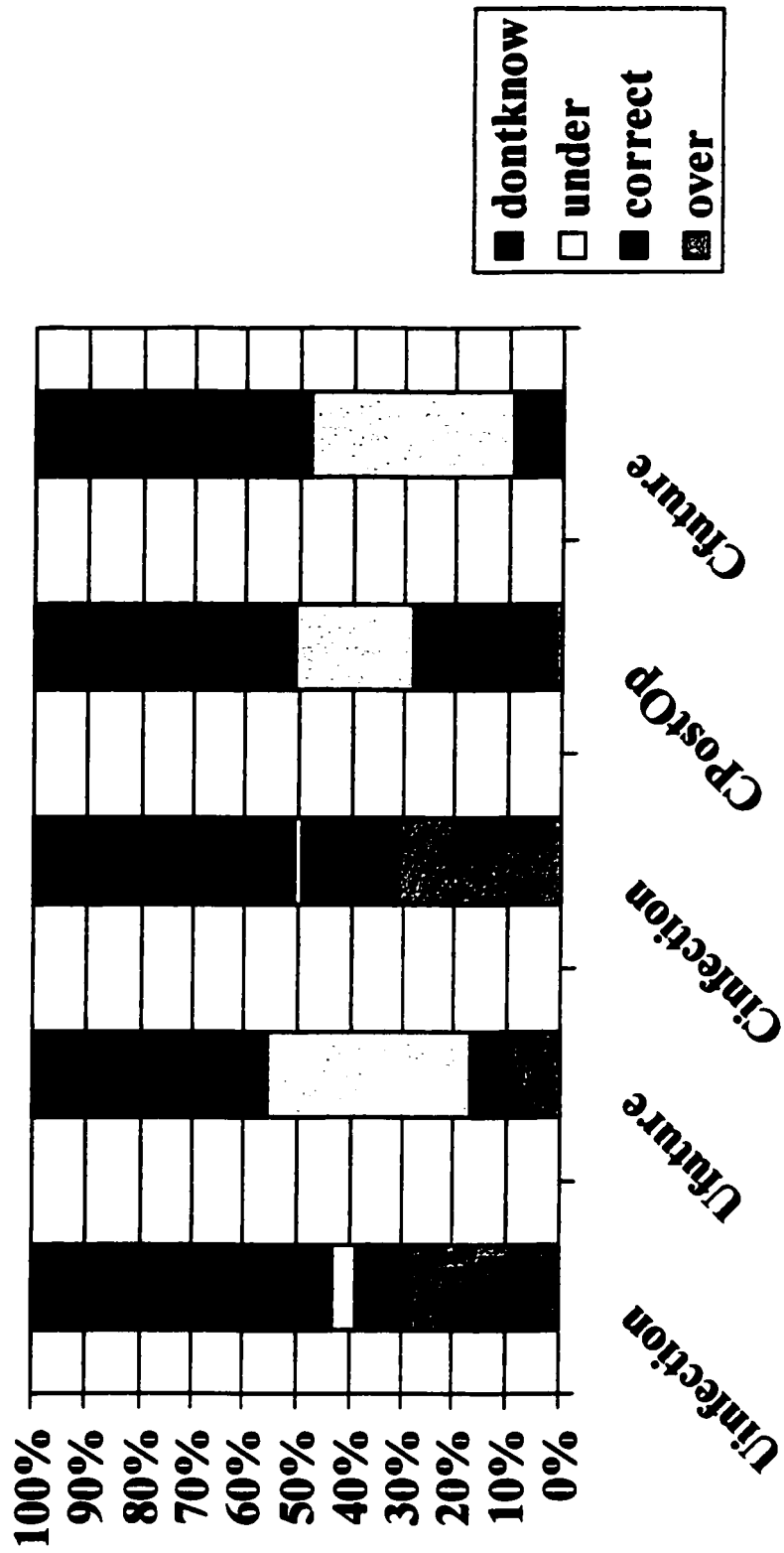


Figure 9. Values: Reasons to Circumcise

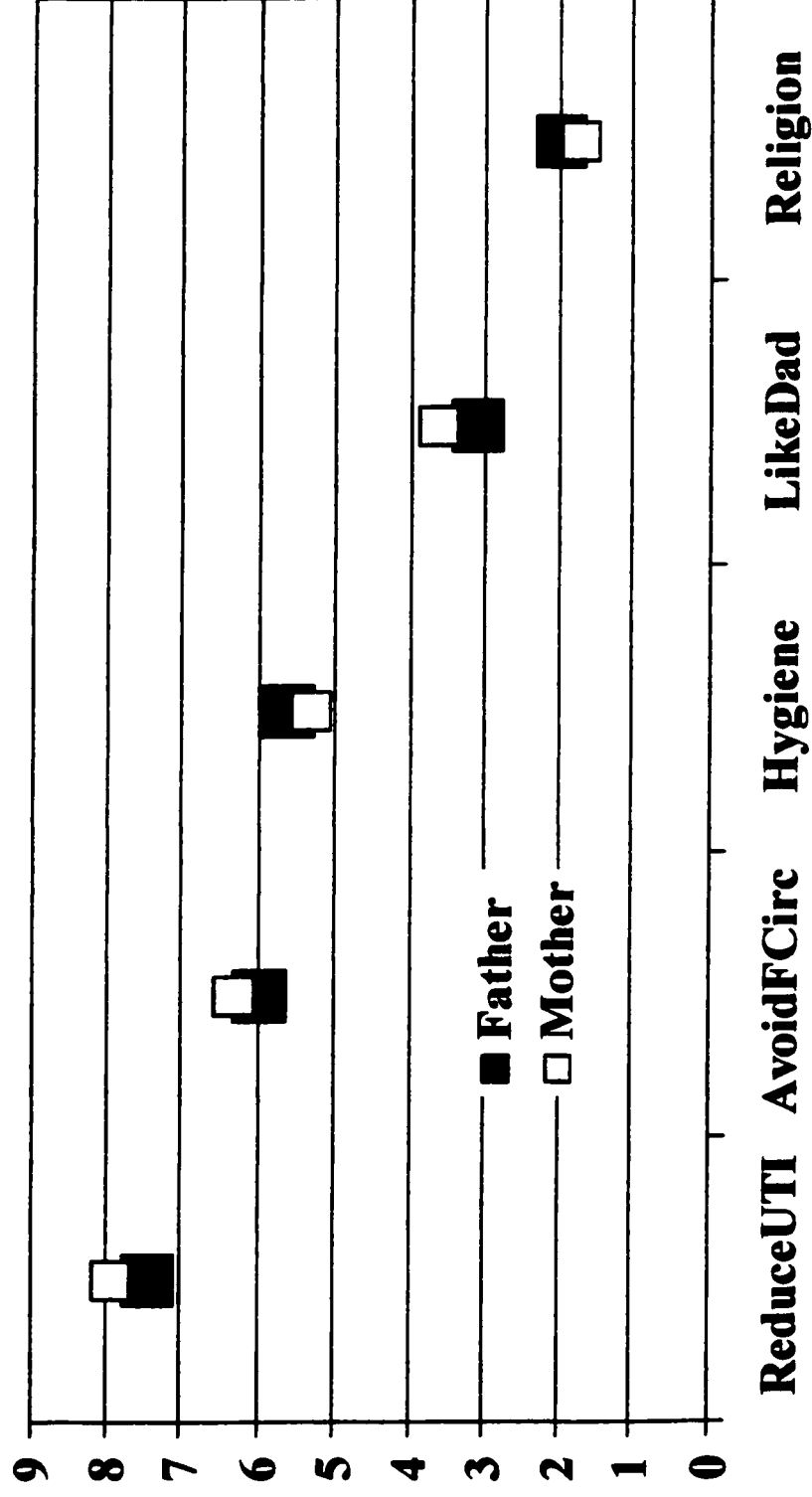


Figure 10. Values: Reasons NOT to Circumcise

