Parental OPEN Decision Making in

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Abstract

Purpose: To study which healthcare professionals (HCPs) first asked parents about their decision regarding circumcision; whether parents felt they were given enough information by their HCP; and what reasons parents cited for their decision.

Study Design and Methods: Bilingual questionnaires were administered to parents and expecting parents of boys (N = 60). Close-ended survey responses were analyzed through factor analysis to ascertain what types of beliefs parents used in their decision making, whether they felt they had enough information, and who first asked them about their decision. Results: Nurses were most likely to be the first HCPs to ask parents about circumcision. Parental personal and cultural

beliefs played an equal or more important role in influencing decision making than medical information received. However, some parents noted that there was a lack of access to accurate information regarding risks and benefits of male circumcision.

Clinical Nursing Implications: Nurses continue to play a critical role in acquisition of knowledge surrounding male circumcision and serve as important liaisons between parents and the proxy consent process. Nurses, as well as other HCPs, should discuss circumcision early in pregnancy so parents have ample time to ask questions, gather information, and make an appropriate decision.

Key words: Circumcision; Informed consent; Neonate.

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ebate among healthcare professionals (HCPs) and ethicists continues surrounding male neonatal circumcision in the United States. Despite evidence suggesting that HCPs are not uniformly in favor of the routinized practice, the procedure is nevertheless upheld and maintained in hospital settings across the United States, which has one of the highest circumcision rates of any industrialized nation (World Health Organization, 2007).

Historically, circumcision was practiced in various societies with its origins dating back millennia (Pinto, 2012). Historical records also show that circumcision was performed as early as 4,000 years ago by Egyptians (Pinto, 2012) and during biblical times by Jews who regarded it as a mark of the covenant between God and Abraham (Henerey, 2004; Lang, 2013). In Western cultures by the late 19th century, physicians regarded circumcision as a way to alleviate "genital irritation" that was believed to cause such illnesses as blindness, gout, hernia, epilepsy, and paralysis (Henerey, 2004). By the mid-20th century, hospitals had replaced homes as the typical place of birthing, and male neonatal circumcision became a routine hospital procedure, rationalized as a way to promote penile hygiene and prevent disease. The belief that the uncircumcised penis was a source of pathology increased the popularity of the procedure so

Circumcision continues to be a common but elective procedure performed on newborn baby boys in the United States.



that by 1960, roughly 95% of boys born in the United States were circumcised (Gollaher, 2000).

As male neonatal circumcision became routinized, risks and benefits became critically debated between those who regarded it as a prophylactic measure against disease and those who saw it as an unnecessary and potentially harmful surgery. The American Academy of Pediatrics (AAP) reported in 1971 that it found "no absolute medical indication for routine circumcision" (p. 110), yet numerous medical studies emerged showing a link between neonatal circumcision and reduced HIV incidence, penile cancer, urinary tract infections, and sexually transmitted diseases (Pinto, 2012).

Conversely, anticircumcision arguments emerged, saying that circumcision was useful only for medical conditions not present in newborns and for diseases potentially acquired later in life. According to this view, neonatal circumcision compromises a child's right to self-determination (Lang, 2013) because the procedure is elective and the child cannot issue informed consent for himself. There are many procedures children cannot consent to but that may directly affect them; parents are obligated and in most cases legally required to make decisions on behalf of their children (Mazor, 2013). Neonatal circumcision is different, however, in that in most cases it is a cosmetic or ritualistic procedure capable of inflicting harm and long-lasting or permanent damage, including physical or emotional disabilities. Studies argue, for example, that the penile foreskin is a healthy and necessary part of the body (Lang, 2013), such that its removal causes a reduction in sexual pleasure for the adult male and compromises his bodily integrity (Lang, 2013; Merkel & Putzke, 2013).

Opponents of circumcision have also argued that the procedure compromises an infant's right to selfdetermination by giving his parents proxy consent over a decision that could be deferred until the adult male can decide for himself (Lang, 2013; Merkel & Putzke, 2013; Pinto, 2012; Sardi, 2011). In the United States, male neonatal circumcision is the most common medical procedure performed without informed consent from the patient himself (Gollaher, 2000; Pfuntner, Wier, & Stocks, 2013). Therefore, it is ethically critical that parents who opt for circumcision and, thus, consent by proxy be given access to information about the benefits and risks of the medical procedure.

In 2012, the AAP Taskforce on Circumcision replaced their policy statement from 1999 in which they opined "the risks do not outweigh the benefits" (AAP, 1999) to an updated statement acknowledging that the health benefits of newborn male circumcision outweigh the risks (AAP, 2012, p. 585). The AAP taskforce did not recommend routine circumcision for all male newborns, but reported that "the benefits of circumcision are sufficient to justify access to this procedure for families choosing it and to warrant third-party payment for circumcision of male newborns" (AAP, 2012, p. 585). The taskforce also acknowledged that "Parents are entitled to medically accurate and nonbiased information about circumcision, and they should weigh this medical information in the

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context of their own religious, ethical, and cultural beliefs" (AAP, 2012, pp. 585–586). Thus, AAP endorses parental proxy consent for circumcision.

Nonmedical factors of religion, ethics, and culture are highly influential in parents' decisions for or against neonatal circumcision. Previous studies have shown that parents tend to make decisions regarding circumcision based on personal, cultural, or religious reasons in addition to or in lieu of medical information (Adler, Ottaway, & Gould, 2001; Binner, Mastrobattista, Day, Swaim, & Monga, 2002; Tiemstra, 1999; Wang, Macklin, Tracy, Nadel, & Catlin, 2010). More recent research by Bisono et al. (2012) and Rediger and Muller (2013) also suggest that although there are a number of health-based reasons that underlie parental decision making, the vast majority of parents report that personal or cultural reasons are among the strongest factors that influence their overall decision.

Nurses can play a role in the decision-making process regarding circumcision based on their proximity to the mother-baby couplet (Kaufman, Clark, & Castro, 2001). Thus, it is important to explore whether expecting parents, who will potentially provide proxy consent for their son's circumcision or refuse the procedure outright, have access to medical information about not only the

Table 1.

Characteristics of Parent Respondents

Gender					
	Female	90.0% (54)			
	Male	6.7% (4)			
	Other	3.3% (2)			
Parental Relationship to Youngest Child					
	Mother	88.3% (53)			
	Father	6.7% (4)			
	Other (stepparent)	6.7% (4)			
Parent Race/Ethnicity					
	Latino/Hispanic	73.3% (44)			
	African American/Black	13.3% (8)			
	White/Caucasian	11.7% (7)			
	Prefer not to answer	1.7% (1)			
Parent Religion (<i>n</i> = 47)					
	Catholic	61.7% (29)			
	Protestant	21.3% (10)			
	Other	17.0% (8)			
Parent Marital Status (<i>n</i> = 58)					
	Single	31.0% (18)			
	Engaged/married	32.8% (19)			
	Separated	1.7% (1)			
	In steady relationship				
	Not living together	10.4% (6)			
	In steady relationship				
	Living together	24.1% (14)			

Note. n = 60 except where noted

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benefits, but the risks of the procedure, and what sources of medical information these parents rely on.

Study Design and Methods

A survey questionnaire, available in both English and Spanish, was administered to a convenience sample of 60 parents or expecting parents at a private obstetrics/gynecology office, a women's health clinic, and a pediatrics clinic. Individuals qualified for participation if they were 18 years of age or older, and were the parent, expecting parent, or stepparent of a male child (hereafter, participants are referred to as "parents"). Parents of sons older than 5 were excluded because recall was unreliable regarding their decision-making process as it had originally occurred. A sample size of 60 was determined sufficient to achieve correlation coefficients that could account for a high degree of variance in the majority of factor loadings in our analysis.

All surveys and information forms for parents and expecting parents were forward translated from English into Spanish by institutional review board (IRB) employees fluent in the regional dialect of our target population. The Spanish survey was then back translated into English by different IRB employees who were also bilingual and fluent in that regional dialect. The survey instrument was based primarily on close-ended questions used in previous classic studies of circumcision attitudes (Adler et al., 2001; Binner et al., 2002; Tiemstra, 1999). Our survey addressed the following questions: (1) Which HCP first asked parents about their decision regarding circumcision? (2) Did parents feel that they were given enough information about the procedure by HCPs? and (3) What were the various factors that influenced parental decision making? Demographic data were also collected at the end of the survey.

The principal author obtained IRB approval through her home institution as well as the affiliated hospitals of the clinics and waiting rooms. The principal author was only allowed access to three hospital pediatric waiting rooms and one obstetrics/gynecology clinic waiting room because of the perceived controversial and sensitive nature of the study. With a research assistant who was fluent in Spanish, the principal author handed out surveys to parents in those waiting rooms and instructed parents to complete it if they wished and to return the materials in a sealed envelope to the receptionist. Thus, parents were allowed freedom and privacy to complete the survey in the waiting room, and the completed surveys were picked up at a later time.

Results

A total of 60 participants completed the parent questionnaire. Table 1 displays percentages regarding biographical data of the participants including their self-identified gender, race/ethnicity, religious affiliation, marital status, and the participant's relationship to the youngest male child. Our convenience sample tended to be homogenous in terms of most demographic data reported, in that the majority of parents self-identified as a mother (n = 53, 88.3%) who was a person of color (n = 52, 86.6%) and who was more likely to identify as Catholic or Protestant (n = 39, 83%).

In response to a question that asked parents to identify which HCPs explicitly asked them about their decision regarding circumcision, nurses were most likely to discuss the actual decision with parents, as shown in Table 2. Parental responses show that nurses (broadly identified as those in clinics, pediatrics, and obstetrics offices) first engaged parents in a discussion about circumcision. Parents were then asked if they felt that their HCPs provided them with enough information regarding circumcision. Forty-four participants (73.3%) felt that they were given enough information, 14 participants (23.3%) believed they were not provided with enough information, and 2 participants (3.3%) were unsure.

To ascertain whether or not parents were likely to have pro- or anticircumcision biases, they were also asked whether or not they believed that the benefits of circumcision outweighed the risks of the procedure, and responded to a Likert-scale response: 17 parents (28.8%) disagreed or completely disagreed, 12 parents (20.3%) were neutral, and 30 parents (50.8%) agreed or completely agreed.

It is also critical to understand parents' reasons for their decision of whether or not to circumcise. Thus, a number of additional close-ended questions measured parents' opinions regarding the actual procedure of circumcision as well as how they felt about a number of common beliefs often cited as reasons for circumcising. This scale, originally developed by Binner et al. (2002), which has an overall Cronbach's alpha reliability of .84, made it possible to measure the extent to which respondents felt that the overall benefits outweigh the risks of circumcision. The scale was coded so that lower scores indicate lower levels of "procircumcision" attitudes.

This scale measured attitudes about whether parents believe that: the benefits of circumcision are greater than the risks; fathers who are circumcised should have boys who are circumcised; circumcision will help keep a baby's penis clean; circumcision will decrease cancer of the penis; circumcision will decrease risk of infection of the penis; circumcision will decrease the risk of contracting HIV/AIDS; circumcision is too painful for infants (a reverse-coded variable); and circumcised penises look better than uncircumcised penises. All variables were measured on a five-point Likert scale, from "Completely Disagree" to "Completely Agree." Although most, but not all, of the statements include language that is biased toward circumcision, it should be noted that parents who did not have a favorable opinion toward the procedure were likely to state that they disagreed with these statements. Responses from each question were included in a principal axis factor analysis, with varimax rotation. As a result, the factor analysis produced two factors, and the eigenvalues for the two rotated factors were 4.0 and 1.1, together explaining 64.0% of the combined variance, as shown in Table 3. Because the analysis controlled for a relatively high percentage of variation, the results remain internally valid despite a small sample size and that such differences in patterns of responses still exist when controlling for other sources of variance.

We labeled the first factor as "cultural," which consisted of six items in which the majority of responses

Table 2.

Which Healthcare Provider(s) Asked Parents About Their Decision to Circumcise or Not Circumcise Their Child

Nurse	29
Obstetrician	16
Pediatrician	10
Midwife	3
Childbirth instructor	1
Waiting room receptionist	1

Note. *n* = 60

demonstrate that personal or cultural expectations affect one's opinions regarding circumcision. Beliefs associated with these "cultural" items include: (1) the benefits of circumcision outweigh the risks; (2) fathers who are circumcised should have boys who are circumcised; (3) circumcision will help keep a baby's penis clean; (4) circumcised penises do look better than uncircumcised penises; (5) circumcision is not too painful for infants (the recoded variable); and (6) circumcision *will decrease* cancer of the penis. The factor analysis demonstrates that if parents believed the benefits of circumcision outweighed the risks, they were also more likely to report that (listed here in rank order): fathers should look like their sons, circumcision assists in cleanliness, circumcised penises look better than uncircumcised ones, circumcision is not too painful for infants, and that circumcision will decrease the risk of penile cancer.

These statements are common arguments given by HCPs and parents alike as to why they believe circumcision to be the "correct" choice. These results also demonstrate that parents tended to think of the (lack of) pain associated with circumcision as well as the risk for penile cancer as *cultural* information, rather than medical information, although terms like "cancer" and "pain" would seem to refer to medical issues. Thus, perceived medical (e.g., cancer) risks and health promotion (e.g., hygiene) issues are likely to be chosen *along with* culturally mediated issues (e.g., bodily aesthetics; father/son matching). It may be that a number of perceived health issues are more likely to be shared via nonmedical sources of information when cultural issues are considered by non-HCPs.

We labeled the second factor as "health," which consisted of two items that expressed opinions relevant to the medical nature of circumcision. These opinions include: (1) circumcision *will* decrease the risk of contracting HIV/AIDS; and (2) circumcision *will* decrease the risk of infection of the penis. Both of these beliefs target specific medical discussions that are associated with circumcision and are both implicated as potential health benefits of the procedure by AAP (2012).

We chose to label the two emerging categories with the terms "cultural" and "health" for several reasons. Parents who were more likely to believe that the benefits of circumcision outweighed the risks also believed that aesthetic reasons for circumcision were of primary importance. The

"cultural" category of factors was labeled as such because it provided a mixture of both aesthetic beliefs and popular health beliefs regarding circumcision, including the notion that circumcision prevents infection and cancer as well as the outdated concept that infants do not feel pain (Simpson, 2006), whereas the "health" category only contained two factors that were more strictly health-based. Overall, results demonstrate that there are two main categories of beliefs that parental responses fell into, and that parents tended to give a mixture of personal/cultural beliefs as well as a few health beliefs that supported their decision. The results of the factor analysis performed on parental attitudes about circumcision broke new ground in this area because the analysis revealed emerging patterns of responses given by parents. Notably, specific perceived health issues were likely to be chosen *along* with culturally mediated issues, which may be the result of how specific types of health information are passed from friends and family members to expecting parents.

Clinical Nursing Implications

Our study demonstrated that nurses are most likely to ask parents about circumcision, but nearly a quarter of the participants (23.3%) stated that they did not receive enough or any medical information about circumcision at the time of survey completion and tended to rely on a mixture of cultural and health-based information to inform their decision. This finding is an important consideration for nurses, in that they have the continuing ability to play an important role in the proxy consent process surrounding circumcision. However, true proxy consent cannot be given to HCPs if a parent has not received enough information about the risks and benefits of the procedure itself. Nurses and other HCPs should also continue to take additional steps to ensure that parents are given information regarding the procedure—early in the pregnancy—even if parents state that they already have information, or if HCPs believe that parents are not interested in such information.

One of the limitations of this study is that the participants were a self-selected group consisting mostly of procircumcision, racial/ethnic minority members. Because, nationally, rates of neonatal circumcision are lower among persons of color (Centers for Disease Control and Prevention, 2011), it is possible that this study underrepresents racial/ethnic minority members who are opposed to neonatal circumcision. Research examining the underrepresentation of minorities in clinical research shows that minorities have often been excluded by the scientific community, but also that minority group members are more reluctant to participate in medical research due to mistrust and fear of past abuses (Noah, 2003). Notably, some parents refused to participate because they stated that the principal researcher did not appear to be of a similar ethnicity. As well, the discussion surrounding informed consent in the United States has tended to exclude racial/ethnic and religious minorities (Matthew, 2008). Laws governing informed consent have evolved to narrowly recognize only patient autonomy, and research has shown that minority groups do not subscribe to the patient autonomy model in the same way as majority members do (Matthew, 2008). Thus, we should not assume, for example, that all parents want all health-based information possible before making the decision to circumcise.

Another limitation of this study involves the gender composition of the sample, in that the majority of

Table 3.

Factor Analysis of Parental Attitudes Toward Circumcision

Variable Name	Statement**	Factor 1: Cultural	Factor 2: Health+
Cultural 1	I believe that the benefits of circumcision are greater than the risks.	0.748	0.319
Cultural 2	Fathers who are circumcised should have boys who are circumcised.	0.847	0.140
Cultural 3	l believe that circumcision will help keep my baby's penis clean.	0.770	0.414
Cultural 4	I believe that circumcised penises look better than uncircumcised penises.	0.747	0.094
Cultural 5*	I believe that circumcision is too painful for infants.	0.753	-0.048
Cultural 6	I believe that circumcision will decrease cancer of the penis.	0.550	0.479
Health 1	I believe that circumcision will decrease the risk of infection of the penis.	0.485	0.633
Health 2	I believe that circumcision will decrease the risk of contracting AIDS.	-0.099	0.882
Eigenvalues		4.0	1.1
Variance Explained		50%	14%

*Reverse-coded variable

**All variables were measured on a five-point Likert scale, from "Completely Disagree" to "Completely Agree."

+The factor analysis was done with a varimax rotation using principal axis factor analysis.

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respondents are female. Although some research on parental decision making regarding circumcision demonstrates that mothers may defer to the fathers of their sons to make this decision or that the father's circumcision status greatly influences a son's circumcision status (Binner et al., 2002; Lee et al., 2003), other research findings have shown that either both parents will make the decision together or that previous studies have not separated mother versus father parental decision making at all (Adler et al., 2001; Tiemstra, 1999). Thus, although we cannot necessarily extrapolate these specific conclusions with the wider population as a whole, these results mirror the findings of many other major studies that measured parental attitudes regarding circumcision (Adler et al., 2001; Binner et al., 2002; Tiemstra, 1999).

Although AAP's (2012) newest stance on male neonatal circumcision states that parents must ultimately decide for themselves based on what they feel is best for their children, our data suggest that parents often do not have the ability to give an informed decision but instead rely on a combination of cultural and culturally informed health information to make the decision. If parents lack accurate, up-to-date information regarding the risks of circumcision, this calls into question whether the proxy consent they provide is truly informed.

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Suggested Clinical Nursing Implications

- All nurses involved in pre- and postpartum care of mothers and babies should have continuous access to accurate, up-to-date information regarding male circumcision, which should involve knowledge including circumcision wound care, intact penis care, and ethics of both the consent process and the procedure itself.
- Nurses should continue to be proactive in offering such information regarding circumcision as early in the pregnancy as possible so that parents have ample time to discuss and research the decision.
- Along with all maternal/infant healthcare providers, nurses should support the parental decision-making process and should offer access to health- and ethics-based information even if parents may initially not be interested. Nurses should not assume that parents already have enough information or that they are not open to acquiring new knowledge.
- Parents should be informed of all risks of the procedure and have access to preoperative and postoperative guidelines during the proxy consent process, which should be carefully documented by nurses or other HCPs obtaining written consent.
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