Continuing Education Module

Informed Decision Making in Maternity Care

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ABSTRACT

In the United States, federal acts and regulations, as well as professional guidelines, clearly dictate that every pregnant woman has the right to base her maternity care decisions on accurate, up-to-date, comprehensible information. Despite these efforts, evidence suggests that informed consent within current health-care practice is restricted and inconsistently implemented. Patient access to evidence-based research is imperative under the scope of informed consent and is particularly important during a time when perinatal mortality and morbidity rates, interventions, and disparities are on the rise in the United States. This article describes the Coalition for Improving Maternity Services' investigation of the breakdown of informed consent in maternity care.

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Keywords: informed decision making, informed choice, informed consent, childbirth choices, patient decision making

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In the United States, federal acts and regulations, as well as professional guidelines, state that every pregnant woman has the right to base her maternity care decisions on accurate, up-to-date, comprehensible information (“A Patient’s Bill of Rights: The American Hospital Association,” 1978; American College of Obstetricians and Gynecologists [ACOG] Committee on Ethics, 2004; Health Insurance Portability and Accountability Act of 1996, 1996; Meng, 2008). Contrary to legal mandates, mounting evidence reveals that the application of informed consent within current health-care practice is restricted and inconsistently implemented (Declercq, Sakala, Corry, & Applebaum, 2006; Jung, Wensing, & Grol, 1997; Levy, 1999b; Marteau, Dormandy, & Michie, 2001). Patients report receiving less information

about treatment options and alternatives than desired and being afforded the opportunity to participate in health-care decisions less than they would prefer (Declercq et al., 2006; Jung et al., 1997; Levy, 1999a; O’Cathain, Thomas, Walters, Nicholl, & Kirkham, 2002; Rosen, Anell, & Hjortsberg, 2001; Rothenbacher, Lutz, & Porzolt, 1997). In addition, practitioners report underestimating patient preferences to participate in health-care decisions (Bruera, Sweeney, Calder, Palmer, & Benisch-Tolley, 2001; Hammond, Bandak, & Williams, 1999; Jung et al., 1997; Rothenbacher et al., 1997) and not integrating informed decision-making principles into practice (Elwyn, Edwards, Gwyn, & Grol, 1999; Hindley & Thomson, 2005), thus highlighting a gap in care.

Access and availability to evidence-based information is central to the legal and ethical sanction of informed consent and is imperative to the improvement of health outcomes, particularly at a time when perinatal mortality and morbidity rates, interventions, and disparities are on the rise in the United States (Martin et al., 2007; Sakala & Corry, 2008). Recent research suggests a correlation between interventions and poor health outcomes (MacDorman, Declercq, Menacker, & Malloy, 2006; March of Dimes, 2006). The current climate of maternity care has provoked mounting political, professional, and public concern (Hicks, Spurgeon, & Barwell, 2003; Sakala & Corry, 2008). The National Department of Health and Human Services' Healthy People 2010 objectives (Keppel, Percy, & Klein, 2004), the Safe Motherhood Initiative (Cook & Dickens, 2001), and the Millennium Development Goals (Shaw, 2006) are just a few of the national and international health goals that contain specific measures to improve maternal and neonatal health outcomes.

In an effort to address the disparities and inequities within current maternity care, the Coalition for Improving Maternity Services, a nonprofit organization with a long-standing commitment to promote a wellness and evidence-based model of care, is investigating the breakdown of informed consent in maternity care. In order to do so, the organization appointed the Evidence in Action Committee (EAC) to examine the barriers to the actualization of informed decision making. The EAC has collected and compiled the research and is working on translating empirical data into resources that are accessible to practitioners and the public so that health-care decisions can be based on the most accurate and up-to-date information as possible.

This article provides an overview of the rationale for investigating the issues of informed decision making and why it is imperative to the health and well-being of childbearing families as well as the maternity care system. The article begins with an explanation of informed consent and historical examination of patient involvement in informed decision making, followed by a summary of research related to the benefits of patient participation in informed decision making. It then reviews the discrepancies between what patients want and what practitioners practice regarding information and choice, with specific attention to maternity care. The article concludes with a discussion of current

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care in the United States and how the EAC is addressing informed decision making.

INFORMED CONSENT

The doctrine of informed consent protects patients' rights to voluntary consent or refusal of any medical treatment, procedure, or intervention based on information regarding the risks, benefits, and alternatives of care. This includes the provision of sufficient, evidence-based information to make a decision that reflects self-determination, autonomy, and control (Cahill, 1998; Cook & Dickens, 2001; Coy, 1989; Guadagnoli & Ward, 1998). Patient consent or refusal is more than a legal doctrine to obtain a patient's signature; it is a process of information exchange and involvement of patients in decision making (Ford, Schofield, & Hope, 2003; Oberman, 2000). See the Table for the essential components of informed consent, according to the American College of Obstetricians and Gynecologists.

The U.S. federal government has established several regulations and laws to protect patients' rights to informed consent and refusal, such as the Health Insurance Portability and Accountability Act of 1996 (1996), the Emergency Medical Treatment and Active Labor Act (1986), and the U.S. Consumer Bill of Rights and Responsibilities regulation (President's Advisory Commission on Consumer Protection and Quality in the Health Care Industry, 1998), as well as the Patient's Bill of Rights ("A Patient's Bill of Rights: The American Hospital Association," 1978).

Patients' rights regarding maternity care choices and access to information is promoted by national and international organizations such as the American College of Obstetricians and Gynecologists (ACOG Committee on Ethics, 2004); the American College of Physicians (Turton & Snyder, 2008); the American Hospital Association ("A Patient's Bill of Rights: The American Hospital Association," 1978); the American Medical Association (Bostick, Sade, McMahon, & Benjamin, 2006); United Kingdom's Department of Health's Changing Childbirth Initiative (Hicks et al., 2003); the United Nations Educational, Scientific and Cultural Organization's Universal Declaration on Bioethics and Human Rights (Meng, 2008); and the World Health Orga-

The Coalition for Improving Maternity Services' Web site (www.motherfriendly.org) is an important resource for educational materials related to informed decision making.

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nization (Cook & Dickens, 2001). The provision of professional guidelines and protocols related to the application of informed consent and refusal has been established for several decades.

HISTORY OF PATIENT INVOLVEMENT IN DECISION MAKING

In order to understand the importance and application of informed consent and refusal within maternity care, it is helpful to examine the historical evolution of patients' rights with regard to information, decision-making authority, and autonomy.

The current health-care system was founded on a paternalistic model in which the physician maintained complete and unquestionable authority over all health-related decisions and information (Mallardi, 2005). The patient was seen as an object and recipient of the physician's medical expertise. The physician acted as the authoritarian benefactor who took care of the patient (Mallardi, 2005). This relationship between patient and physician prevailed, uninterrupted for centuries. In fact, many argue that the paternalistic model not only still exists, but thrives in today's health-care systems (Arslanian-Engoren, 2002; Cody, 2003; Wittmann-Price, 2004). The American College of Obstetricians and Gynecologists recognizes the problematic existence of the paternalistic model in current obstetric care as a "historical imbalance of power in gender relations [that constrains] individual choice posed by complex medical technology, and the intersection of gender bias with race and class bias in the attitudes and actions of individuals and institutions" (ACOG Committee on Ethics, 2004, p. 13).

The first acknowledgment of patient autonomy in health care was in 1914 as a result of the pivotal case, *Schloendorff versus Society of New York Hospitals* (Lurvey, Nager, & Johnson, 1996). In this case, the physician removed the patient's fibroid tumor when she had only consented to an examination under anesthesia. The judge proclaimed the patient's entitlement to self-determination, which marked the beginning of the legal foundation for patient rights in health care and the mandatory protocol to obtain patient consent (Lurvey et al., 1996; *Schloendorff v. Society of New York Hospitals*, 1914).

TABLE
The Essential Components of Informed Consent*

Comprehension
<ul style="list-style-type: none"> Clinician must assure that s/he has: <ul style="list-style-type: none"> Awareness and understanding of the patient's situation and possibilities Used language that is understandable to the patient
Adequate information
<ul style="list-style-type: none"> Clinician must give adequate information regarding: <ul style="list-style-type: none"> Diagnosis Prognosis Alternative treatment choices, including no treatment
Freedom of choice
<ul style="list-style-type: none"> Patient must be free to/of: <ul style="list-style-type: none"> Give consent freely, intentionally, and voluntarily Authorize provider to perform the procedure Coercion Pressure from forces beyond herself Choose among options including other than what may be recommended

*According to the American College of Obstetricians and Gynecologists. "If [free consent] is to be operative at all in the course of medical treatment, it presupposes knowledge about and understanding of all the available options" (ACOG Committee on Ethics, 2004 p. 11).

In 1957, the concept of informed consent was conceived as a result of the famous *Salgo versus Leland Stanford Jr. University Board of Trustees* case. This was the first time that the importance of patients being informed in order to consent to medical care was legally acknowledged. As a result of this case, the court established the legal doctrine of informed consent that held physicians liable for withholding any information necessary for the patient to consent to treatment. Additionally, the physician may not minimize any known dangers of a procedure in order to induce consent (*Salgo v. Leland Stanford Jr. University Board of Trustees*, 1957).

As monumental as this ruling was for patient rights, it was also problematic for practice protocols. Within the ruling, the judge stated that "a certain amount of discretion must be employed consistent with the full disclosure of facts necessary to an informed consent" (*Salgo v. Leland Stanford Jr. University Board of Trustees*, 1957, 5.(b) para. 1). Negotiating practice policy that reflects discretion and full disclosure of information was left to the physician, which, in essence, gave the physician authority to undermine the legal sanction of providing information to the patient.

Clarification regarding physicians' legal responsibilities to disclose all information on the risks, benefits, and alternatives to patients prior to treatment was not specified and put into practice until

the 1980s (Mallardi, 2005). The shift from physician authority to patient autonomy was coupled with a public and political movement that emphasized patient access to information, choice, and personal control regarding individual medical care (Mallardi, 2005).

At this time, the focus of health care on a patient's physical well-being was expanded to include concern for the patient's autonomous capacity to make health-care decisions. This shift was paramount in reshaping the previous paternalistic model of care and giving way to the current ethical and legal doctrines of informed consent. Federal acts and regulations, as well as professional guidelines, clearly demonstrate that every pregnant woman has the right to base her maternity care decisions on accurate, up-to-date, comprehensible information.

Making informed choices during childbirth can be complex and multilayered. The process involves the integration of evidence-based information with individual health-care needs, values, beliefs, and preferences (Michie, Dormandy, & Marteau, 2003). Adequate information regarding the risks, benefits, and alternatives is necessary for true informed decision making, particularly in light of mounting evidence regarding risks related to the prevalent use of interventions.

Over 1 million women a year give birth via cesarean section (30% of all births) (Martin et al., 2007). According to the *Listening to Mothers II* survey (a national study conducted to gather information about women's attitudes, feelings, knowledge, and experiences in the U.S. maternity care system), 76% of women reported having an epidural, 47% were given pitocin (synthetic oxytocin), and 56% were catheterized (Declercq et al., 2006; Martin et al., 2007). Rising intervention rates underscore the importance of physicians' legal and ethical obligation to ensure all women fully understand the related potential risks, benefits, and alternatives so they can make informed choices. Not only is this right legally sanctioned, a review of research related to patient involvement in decision making reveals numerous systematic and individual benefits, highlighting the positive implications associated with informed decision making.

The benefits related to the overall sustainability of the health-care system are noteworthy for several reasons. It has been deemed important for policymakers and physicians to pay attention to patient preferences, experiences, and expectations (Hicks et al., 2003), particularly in a time when patients

take an active, consumer-like role regarding the selection of health-care practitioner and place of care (Cahill, 1998; O'Cathain et al., 2002; Singh, Newburn, Smith, & Wiggins, 2002).

BENEFITS OF INFORMED DECISION MAKING

Research indicates that congruency between patients' and physicians' decision-making styles is associated with higher patient evaluation of physicians, as well as an increased likelihood of patient recommendations to others (Krupat, Hsu, Irish, Schmittiel, & Selby, 2004). In addition, patient participation in health-care decisions is positively correlated with improvement to patient-physician relationships (Levy, 1999a; Spurgeon, Hicks, & Barwell, 2001) and trust in the physician (Krupat et al., 2004; Levy, 1999a). All of these factors contribute to patient satisfaction and allegiance to health practitioner and place of care, contributing to the overall sustainability of the health-care system.

Numerous physiological benefits are associated with patient involvement in decision making. For example, research correlates overall quality of life, including physical and social functioning (Hack, Degner, Watson, & Sinha, 2006), increased adherence to treatment plan, and improved clinical outcomes (Loh, Leonhart, Wills, Simon, & Härter, 2007) with patient involvement in decision making. Research specific to childbirth suggests an increased sense of responsibility for health of self and baby (Harrison, Kushner, Benzies, Rempel, & Kimak, 2003), as well as shorter recovery periods (Green & Baston, 2003) with patient involvement in decision making.

Several psychological benefits, such as increased patient satisfaction and perception of experience (Christiaens & Bracke, 2007; Goodman, Mackey, & Tavakoli, 2004; Green & Baston, 2003; Green, Coupland, & Kitzinger, 1990; Hodnett, 2002; Knapp, 1996; Lavender, Walkinshaw, & Walton, 1999), enhanced emotional well-being (Green et al., 1990), and increased sense of patient empowerment and self-esteem (Jomeen, 2004; Spurgeon et al., 2001) have been associated with patient decision-making involvement and patient control. Implications specifically related to patient involvement in childbirth decisions and patient control include lower levels of fear (Green & Baston, 2003; Green et al., 1990) and less depressive and posttraumatic stress symptoms after birth (Jomeen, 2004).

Research also indicates a woman's maternal participation in informed decision making has an

impact on her child's health and well-being. Green et al.'s (1990) pivotal study examining women's expectations, experiences, and psychological outcomes of birth was the first to establish a correlation between patient access to information and patient control with maternal feelings toward her newborn. This study found that women who self-reported a "sufficient amount" of information, and women who felt in control, used more positive words to describe their babies than women who had an "insufficient amount" of information and lower levels of control (Green et al., 1990).

Patient participation in informed decision making during childbirth may have a positive effect on a child's long-term health and well-being. The relationship between primary caregiver and child is instrumental in laying the foundation for the development of a child's sense of self, others, relationship skills, self-regulation, and emotionality (M. Klaus, Kennell, & P. Klaus, 1995; Schore, 2003; Verny, 2002). According to research from the field of neurobiology, a child's brain is in a critical period of development during the prenatal period through age 5 years (Schore, 2003). Research in psychoneurobiology and attachment theory have demonstrated that brain development during this early period is relationally dependent, and the woman's maternal perception of her newborn can impact the child's short- and long-term health and development (Bowlby, 1988; Schore, 2003).

Despite the substantial benefits associated with informed decision making, the clarity of the legal and ethical standards of informed consent, and the international push to improve patient access to information and choice, the application of informed decision making into today's health-care practice is not clear or consistent (Oberman, 2000).

INCONGRUENCIES IN CURRENT CARE

Research across health specialties indicates that patients receive less information about treatment options and alternatives than desired and are afforded the opportunity to participate in health-care decisions less often than they would prefer (Declercq et al., 2006; Jung et al., 1997; Levy, 1999a; O'Cathain et al., 2002; Rosen et al., 2001; Rothenbacher et al., 1997). These findings are dis-

turbing, especially because access to information and participation in health-care decisions are both central aspects of informed choice.

Compared to the past, more active, information-seeking patients are requesting the opportunity to participate in health-care decisions (Cahill, 1998; Jung et al., 1997; McGregor, 2006; Michie et al., 2003; O'Cathain et al., 2002; Pelkonen, Perala, & Vehvilainen-Julkunen, 1998; Rosen et al., 2001; Singh et al., 2002). Female patients of childbearing age report wanting more information and decision-making participation than any other group of patients (Bruera et al., 2001; Jung et al., 1997; Krupat et al., 2004; Rothenbacher et al., 1997; van der Hulst et al., 2007). *Listening to Mothers II* reports that 80% of the women surveyed desired information about every possible childbirth complication, and 96% indicated they wanted to be involved in the decisions related to their labor and birth, assuming there are no medical complications (Declercq et al., 2006). A similar study in the United Kingdom reported comparable findings: Among the study's first-time mothers, 70% wanted to know as much information as possible related to maternity care choices (Singh et al., 2002).

Patient participation in informed decision making is dependent on more than just women's preferences for information and involvement (Guadagnoli & Ward, 1998). It is dependent on the availability and accessibility of choices and alternatives. Research indicates that authoritative knowledge—the consensual value and acceptance of one knowledge system over all others despite the existence of equally credible and parallel systems of knowledge—plays a major role in when and how patients are afforded the opportunity to make informed health-care choices (Jordan, 1997). The application of authoritative knowledge, health practitioner support, and practice protocols are influential factors in the actualization of patient participation in informed decision making (Charles, Gafni, & Whelan, 1997; Pelkonen et al., 1998; Wirtz, Cribb, & Barber, 2006).

Contradictory to patients' reports of wanting information and decision-making authority, empirical evidence from various health specialties indicates that the majority of physicians underestimate patient preferences to participate in health-care decisions (Bruera et al., 2001; Hammond et al., 1999; Jung et al., 1997; Rothenbacher et al., 1997). In addition, physicians report not being trained to involve patients in health-care decisions (Elwyn et al., 1999) and not integrating informed

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decision-making principles into practice (Elwyn et al., 1999; Hindley & Thomson, 2005). These findings may help us better understand several findings of *Listening to Mothers II*. Seventy-five percent of the women surveyed reported understanding their right to consent or refuse care, but most of the women were unable to accurately describe the risks of common procedures such as induction of labor and cesarean section, and only 18% of women who had episiotomies reported that they participated in making the decision (Declercq et al., 2006).

Another area of divergence between what patients want and how practitioners practice relates to the patient's ability to freely make choices without coercion, an integral aspect of informed choice. As part of the *Listening to Mothers II* study, all women were asked if they felt pressure from a health-care practitioner to be induced, to have an epidural, or to have a cesarean section. Women who had a cesarean section were more likely to indicate feeling pressure from a health-care practitioner to have an intervention than women who had a vaginal birth (Declercq et al., 2006). The prevalence of interventions in maternity care, coupled with the associated potential risks, suggests that informed choice is critical and that all patients should have the opportunity to make maternity care decisions without pressure, coercion, or manipulation.

High rates of childbirth interventions are increasingly being questioned. The March of Dimes (2008) has expressed concern about iatrogenic prematurity due to rising rates of cesarean sections and induction of labor. In addition, research suggests a positive relationship between rising rates of cesarean sections and infant mortality rates (MacDorman et al., 2006).

There is increasing discussion that the rising cesarean rates are the result of a dramatic increase in maternal demand for primary cesareans. The National Institutes of Health's (2006) "State-of-the-Science Conference Statement: Cesarean Delivery on Maternal Request" addressed this issue. The *Listening to Mothers II* survey provides the only national data available on maternal demand cesarean. Less than 2% of first-time mothers reported requesting a cesarean without a medical indication (Declercq et al., 2006).

The rise of national cesarean rates coupled with the drastic decline in vaginal birth after cesarean suggest practice and policy protocols favor the propagation of cesarean sections with no medical reason (Jukelevics, 2008; Wagner, 2000) rather than

maternal choice. According to Gene Declercq, "Cesareans have not only been rising for no indication, they have also been rising for virtually every medical indication, suggesting a practice change in obstetrics to perform cesarean section more liberally" (Barclay, 2004, p. 2). Rising cesarean rates coupled with low maternal request reports further illuminate a gap in care between patient choice and practice protocols.

PROMOTION OF INFORMED DECISION MAKING IN MATERNITY CARE

The Coalition for Improving Maternity Services' EAC recognizes the promotion of evidence-based information and choice in maternity care is not a simple task, yet it is imperative to maternity care reform. The committee is developing a multitier, comprehensive approach that includes efforts to support systematic change and enhanced physician education and awareness, as well as patient education and empowerment.

As part of the committee's goals, EAC is in the process of developing the following: education resources in multiple languages and literacy levels (for patients and providers); a review of legal cases pertinent to informed decision making, including research regarding the legal implications related to creating specific informed consent forms for maternity care (available to patients and providers); and a literature review of empirical research. Additionally, EAC is in the process of investigating issues related to professional accountability, ways to measure informed consent and refusal protocols in health care, and methods to enhance professional understanding and application of informed decision making into maternity care.

The committee is strategizing a "top-down" and "bottom-up" approach that involves patient and practitioner education resources, tools to enhance informed decision making, specific materials and resources for childbirth educators, and methods to institute systematic change. Partnering with the plethora of already existing evidence-based resources, Web sites, and services that promote education and awareness of informed decision making during maternity care is key as EAC's work moves forward.

In future investigations, researchers are encouraged to examine whether there is a relationship between informed consent and patient involvement in

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informed decision making and infant and maternal mortality, perinatal mortality, and prematurity. Additional future research may examine whether a lack of informed decision making is a factor in the routine use of medical interventions, persistent perinatal health disparities, and poor maternal–infant health outcomes.

In summary, the importance of informed decision making in maternity care cannot be overstated. Research demonstrates that patient involvement in childbirth decisions has positive effects for mother, baby, family, and society on many levels. The current proliferation of evidence-based information along with rising national intervention rates, perinatal mortality and morbidity rates, and high disparities within the United States (Hicks et al., 2003; Sakala & Corry, 2008) demand further investigation and the development of ways to address the current gap in what is legally mandated versus what is practiced in maternity care. The Coalition for Improving Maternity Services recognizes the central role that informed consent and informed decision making play in the process of improving health outcomes and is committed to promoting informed decision making via a multitier, comprehensive approach that addresses patients, practitioners, and the overall health-care system.

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