

Outline for  
5-CD Audio Self-Learning Package

When Ethics and Evidence Collide:  
Solving Breastfeeding Problems

by  
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## 5-CD Audio Self-Learning Package

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## **I. Ethical Conduct and Problems, Obstacles, and Facilitators: An Introduction for Lactation Experts**

### **Objective**

Describe obstacles to and facilitators of the classic ethical principles associated with health care. (30 minutes)

*Morals* are the values that we attribute to a system of beliefs that help the individual define right versus wrong, good versus bad.<sup>1</sup>

*Ethics* are the decisions, choices, and actions (behaviors) we make that reflect and enact our values.<sup>1</sup>

*Ethics* can be categorized as meta-ethics, normative ethics, or applied ethics. Meta-ethics addresses the origins of our ethical principles, focuses on the universal truths, the will of God, the role of reason in ethical judgments and the meaning of ethical terms. Normative ethics focus on moral standards that regulate right and wrong behavior or conduct, including habits, duties, and consequences. Applied ethics deal with ethical problems.<sup>1</sup>

### **A. Normative Ethics: Ethical Conduct**

1. Consequentialist Approaches to Ethical Conduct
  - a. Personal benefit: acknowledge the extent to which an action produces beneficial consequences for the individual in question.
  - b. Social benefit: acknowledge the extent to which an action produces beneficial consequences for society.

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<sup>1</sup> This and other definitions are available at < <http://www.ethics.org/resource/ethics-glossary>>

2. Duty-Based Principles to Ethical Conduct
  - a. **Benevolence:** help those in need.
  - b. **Paternalism:** assist others in pursuing their best interests when they cannot do so themselves.
  - c. **Harm:** do not harm others.
  - d. **Honesty:** do not deceive others.
  - e. **Lawfulness:** do not violate the law.
  - f. **Autonomy:** acknowledge a person's freedom over his/her actions or physical body.
  - g. **Justice:** acknowledge a person's right to due process, fair compensation for harm done, and fair distribution of benefits.
  - h. **Rights:** acknowledge a person's rights to life, information, privacy, free expression, and safety.

## B. Applied Ethics: Ethical Problems

### 1. Three Types of Ethical Problems

Ruth Purtilo<sup>2</sup> delineates 3 types of ethical problems: Ethical dilemmas, ethical distress, locus of authority.

- a. Ethical Dilemmas
    - (1) There is no one right thing to do.
    - (2) No win-win situation.
  - b. Ethical Distress
    - (1) There is a right answer, and you know what it is.
    - (2) But for one reason or another, your “hands are tied” to carry out that action.
  - c. Locus of Authority
    - (1) Unclear who should be “in charge” of making the ethically-loaded decision.
    - (2) Question: Is the mother “in charge” of making the decision?
- ### 2. Facilitators of Ethical Decision-Making
- a. Professional Mechanisms for Ethical Conduct
    - (1) Reflection With Respected Colleagues
  - b. Professional Code of Ethics for Different Disciplines
    - (1) For example, from the American Dietetics Association:  
From ADA:
    - (2) “The dietetics practitioner is alert to situations that might cause a conflict of interest or have the appearance of a conflict. The dietetics practitioner provides full disclosure when a real or potential conflict of interest arises.”
  - c. Ethics Committees
    - (1) Originally these were developed because of “legal, regulatory, and professional forces...as an alternative to litigation.”<sup>3</sup>

- (2) However, there are now other reasons, including clients' rights "to live by their values, and the relevance of those values for medical decision making."<sup>3</sup>
- (3) Major Ethical Theories Knowing basic tenets of major ethical theories helps us understand why different individuals make different decisions about which "right" action to take.

### 3. Major Ethical Theories

#### a. Situation-Based Approaches to Ethics

- (1) Casuistry
- (2) Situation-based, or Circumstances-Based ethics
- (3) Based on the idea that the specific case at hand, and that the circumstances inform moral principles, not vice versa.
- (4) Most easily applied to dilemmas in health care; unique cases.

#### b. Action-Based Approaches to Ethics

- (1) Deontology
  - (a) Duty-driven.
  - (b) Considers that some acts are right or wrong independent of their consequences.<sup>4</sup>
  - (c) Famous deontologist was Immanuel Kant.
- (2) Teleological (Consequentialism)
  - (a) *Action-driven.*
  - (b) Considers the consequences of an action before deciding which action is the right action to take.
  - (c) Utilitarianism is the most common teleological theory. This theory considers the greatest good for the largest number of people. It also answers the question: What should I do and why should I do it?<sup>4</sup>
  - (d) (Consequentialism largely considers societal vs. personal benefit.)

#### c. Agent-Based Approaches to Ethics

- (1) Principlism (also called Virtue Ethics or Intuition)
  - (a) *Character driven.*
  - (b) Also called Virtue Ethics or Intuition
  - (c) Contrary to other ethical theories, Principlism dictates what kind of person one ought to be, rather than what they do. Focus is on the character (goodness) of the person.<sup>4</sup>
  - (d) Based on the four fundamental moral principles as set forth by Beauchamp and Childress.<sup>5</sup> These so-called "Big Four" principles of autonomy, beneficence, non-maleficence, and justice were the originals; veracity and confidentiality/privacy have been added.
- (2) Examples of Agent-Based Ethics for IBCLC
  - (a) Quoting a fee in terms of 15-minute intervals
  - (b) Reporting a colleague who is too drunk to practice
  - (c) Promising that a product will solve a problem; it may not
  - (d) Reporting suspected child abuse
  - (e) Knowing the difference between blabbing (i.e., breaching confidentiality) and talking in generalities about clinical lesson-learned where the person cannot be identified.

- (f) Not assuming primary responsibility for the client's healthcare, not prescribing, not taking on decisions that require a medical license.
- (g) Other

Principle	Description	Example
Beneficence (benevolence)	Doing good	
Nonmaleficence	Having its origins in Hippocrates <i>Primum non nocere</i> (First, do no harm),	One would do harm if one practiced without being competent (#8), outside of his/her qualifications (#9) or, when physical or mental impairment affected judgment (#19.)
Lawfulness	Do not violate the law.	The professional has a duty to be a law-abiding citizen and to submit to disciplinary action if he/she has violated the law (#21.) Theft of intellectual property is punishable by the legal system and by the IBLCE's disciplinary committee
Autonomy	The capacity to have the say-so about your own well-being. <sup>2</sup>	The professional must give clients enough information for them to make an informed decision (#11, possibly #12), and present the information without personal bias (#18.) (Question: Can a newborn do this for himself?)
Veracity (sometimes called Honesty)	Duty to tell the truth. Immanuel Kant would contend that this is always supremely necessary.	Not fulfilling one's commitments (#3), lacking in honesty or integrity (#4), engaging in false advertising (#10), providing false or misleading information about products (#12), defrauding third-party payers (#13), using a credential one has not earned (#14) are all practices that deceive others.
Privacy, Confidentiality (sometimes lumped together as "Rights" which then address the client's "personhood.")	Acknowledging a person's rights to life, information, privacy, free expression, and safety	A client has a right to competent care (#7), information (including informed consent), privacy or confidentiality (#6, #20, #23) and to be treated without bias (#2) as a unique individual (#1).
Faithfulness	Entails meeting the patient's reasonable expectations	Purtilo <sup>2</sup> says the patient can expect 5 reasonable things from health care professional.
Justice	A person has a right to legal justice and ethical distribution of goods.	Two types: Comparative justice and lottery. <sup>4</sup> An example might be malpractice insurance, which is not required by IBLCE. <sup>6</sup>
Social Benefit vs. Personal Benefits	The great amount of good for the most amount of people (utilitarianism)	Social benefit and personal benefit address the whole area of conflict of interest (#5, #15, #16, #17.) (Conflict of interest and lack of informed consent are probably the <b>biggest barriers</b> to ethical decision-making.) The World Health Organization's Code of Marketing of Breastmilk Substitutes <sup>7</sup> is really about societal benefits, and the IBCLC is required to adhere to its provisions (#22, #24.)

The numbers refer to the principle listed in the IBLCE Code of Ethics.

(FYI: Don't even **think** about photocopying and giving away the above table, which took me the greater part of 8 hours to create! That would be a copyright violation!)

- d. Variations and Additions to “Big Four” Ethical Principles
  - (1) Purtilo<sup>2</sup> makes a distinction; she says that *confidentiality* is “the practice of keeping harmful, shameful, or embarrassing patient information within proper bounds. Confidentiality always involves a relationship (while privacy does not.)” She does not define privacy, but the Institute for Health Ethics sums it up by saying that *privacy* is “respecting the *self* of others.”<sup>4</sup>
  - (2) “Rights” cuts a bigger swath, as it could include the right to life, the right to respect (especially important in cultural issues) and might spill onto fidelity because client has a right to expect that you’ll do what you promised.
- Purtilo<sup>2</sup> says the patient can expect 5 reasonable things from you, the health care professional, namely that you will:
  - (3) show basic respect (e.g., respecting a person’s modesty)
  - (4) be competent in your care-giving.
    - (a) adhere to the statement you have subscribed to as a member of your profession, most notably, your Code of Ethics.
    - (b) follow the policies and statements of your place of employment.
    - (c) honor what the two of you have agreed to, e.g., informed consent, confidentiality, etc.
- 4. Obstacles to Ethical Decision-making
  - a. Conflict of Interest
  - b. Lack of Informed Consent
  - c. Other Obstacles
    - (1) “I did it for you.”
    - (2) Fear of confrontation (and fear of “whistle-blowing.”)
    - (3) “Everyone is doing it.”
    - (4) “If it’s necessary, it’s ethical” as a potential obstacle.

## C. Summary

1. Ethical conduct and ethical problem-solving are in everyday practice. There are 3 types of ethical problems, and perhaps without even realizing it, we react to these problems based on one or more ethical theories.
2. There are multiple facilitators, and multiple obstacles, to ethical conduct and ethical decision-making.



## II. Conflict of Interest: Who, Me?

Marie Biancuzzo RN MS

Author: *Breastfeeding the Newborn: Clinical Strategies for Nurses (2<sup>nd</sup> ed.)*

Objective: Recognize how the sale and marketing of commercial feeding products poses a conflict of interest and an ethical problem for the healthcare provider. (60 minutes.)

### A. Definitions

1. Michael McDonald at the Center for Applied Ethics defines a conflict of interest as "a situation in which a person, such as a public official, an employee, or a professional, has a private or personal interest sufficient to appear to influence the objective exercise of his or her official duties."
2. **Conflict of Interest** exists when the person in a position of trust is required to exercise judgment on behalf of others (people, institutions, etc.) and when she also has interests or obligations of the sort that might interfere with the exercise of her judgment, and which she is morally required to either avoid or openly acknowledge.<sup>1</sup>
3. Examples
  - a. *Example:* A lactation consultant offers instruction and counseling and also sells/rents breast pumps and equipment.
  - b. *Example:* An academic researcher accepts funds from entities; this may interfere with the conclusions or the slant of the data that he or she reports in a published study.

### B. Conflict of Interest: Several Examples

1. Having Exclusive Contracts with Corporations
  - a. makes you most knowledgeable about their product. Formula, pumps, whatever...is this okay?
  - b. Can make you more willing to participate in product placement for the vendor.
  - c. Do you have an exclusive contract with a pump company?
  - d. Could it affect your description of the product?
2. Accepting Corporate Funding and Products for Scholarly Work
  - a. Competing interests and the price of information can be a slippery slope.<sup>8,9</sup>

- b. Investigators are more likely to report positive results about a product when its maker has funded the study.<sup>10</sup>
  - c. Readers are less likely to believe articles that disclose a competing interest.<sup>11,12</sup>
  - d. What about issue of faculty and institutional review boards?<sup>13</sup>
  - e. Publishing and practice is an issue.<sup>14</sup>
  - f. Industry financing influences publication; a long-standing and real problem<sup>15,16</sup> Companies spend billions of dollars each year to market to physicians.<sup>17</sup>
  - g. How about the landmark study by Ramsay<sup>18</sup> and colleagues?
  - h. Is it okay to accept a product (e.g., formula) to conduct a study?
  - i. *Lancet* has specific rules for authors, editors, and reviewers that govern how to manage conflicts of interest.<sup>19</sup>
3. Accepting Corporate Samples, Gifts, and Tshotcke
- a. Violation of WHO Code<sup>7</sup> is a real<sup>20</sup> and ongoing problem.<sup>21-23</sup>
  - b. There are no “free lunches.”<sup>24</sup> Money comes from somewhere.
  - c. The WHO International Code of Marketing of Breastmilk Substitutes<sup>7</sup> defines both samples and supplies.
    - (1) “**Samples** are single or small quantities of a product provided without cost. These are given as sales inducements.”
    - (2) “**Supplies** are quantities of a product provided for use over an extended period, free or at a low price, for social purposes, including those provided to families in need.”
  - d. What about if you give out formula and/or discharge packs in the hospitals? Does this make you in violation of the Code?
4. WHO Code is a code of *marketing*. Focus: Marketing!
- a. Code does not address efficacy of formula
  - b. Code does not address *purchase* of formula
5. Accepting Government Grants for Scholarly Work
- a. Federal \$ for breastfeeding being used to make formula more like human milk?<sup>25</sup>
  - b. The Health and Human Services office (HHS)<sup>26</sup> and the National Institute of Health (NIH)<sup>13,27-29</sup> have gotten into this!
6. Disclosing Off-Label Uses
- a. Do we need to worry about disclosing off-label recommendations?
  - b. Examples of off-label recommendations?

7. Direct-to-Consumer Advertising and Product Placement
  - a. Product placement is a form of advertising where branded goods or services are placed in a non-ad context, such as movies, the story line of television shows, or news programs. ...
  - b. What about direct-to-consumer advertising?<sup>30</sup>
  - c. What about retractable badge holders, pens, pads, bear for your scope, etc.?
  - d. When you mention a brand name, you are advertising. Because patients trust and respect health care professionals, product endorsement is an ethical consideration.<sup>31</sup>
8. Selling Equipment When You Offer a Service
  - a. In the process of offering a service, you recommend a product that would help the client. And oh-by-the-way, you happen to sell the product.
  - b. This is a conflict of interest. You may choose to exhibit ethical or unethical conduct, but it is a conflict of interest, by definition!
  - c. Ways to be ethical in this situation

### **C. What is Our Responsibility?**

1. We need to look at the Code of Ethics for the certification(s) and/or license(s) that we hold.
2. Look up your own Code of Ethics for that profession.
  - a. Nurses, check out [http://www.nursingworld.org/ethics/code/protected\\_nwcoe303](http://www.nursingworld.org/ethics/code/protected_nwcoe303).
  - b. Dietitians, check out Code of Ethics for the profession of dietetics<sup>32</sup> or visit [http://www.med.howard.edu/ethics/handouts/american\\_dietetic\\_association\\_pr.htm](http://www.med.howard.edu/ethics/handouts/american_dietetic_association_pr.htm)
  - c. IBCLCs, check out [www.iblce.org/professional-standards](http://www.iblce.org/professional-standards)
  - d. Other statements?

### **D. Summary**

1. Sale and marketing of commercial products may constitute a conflict of interest because science (healthcare) and industry have been strange bedfellows for years.
2. Sale and marketing of commercial feeding products poses an ethical problem for many of us because of situations where “your hands are tied” (i.e. ethical distress) or you are not the one who makes the ethically-loaded decision (locus of authority.)



### III. What's Mine is Not Yours: Avoiding Intellectual Property Violations

Marie Biancuzzo RN MS

Author: *Breastfeeding the Newborn: Clinical Strategies for Nurses (2<sup>nd</sup> ed.)*

#### Objective

Recognize and avoid common violations of intellectual property rights. (60 minutes)

#### A. Brief History of Intellectual Property Rights

The World Intellectual Property Organization defines intellectual property as “creations of the mind: inventions, literary and artistic works, and symbols, names, images, and designs used in commerce.”

1. Issue of Intellectual Property Rights (IPR) was first raised in 1873. The Paris Convention for the Protection of Industrial Property was signed in 1883; this was done through an international convention and covered patents, trademarks, and industrial designs.
2. In 1886, the definition of IPR expanded to include copyright as an intellectual creation.
3. In 1967, the World Intellectual Property Organization (WIPO), a specialized agency of the United Nations, was established with the Paris and Berne Conventions. Currently, the WIPO has two major categories of intellectual property:
  - a. **Industrial property** (inventions, trademarks and industrial designs)
  - b. **Copyright** (literary works, plays, songs, photographs, etc.)

#### B. Hot Issues for the Lactation Community

These are by no means the only issues, but some of the most common issues. *I am not an attorney and this handout is not legal advice.* To protect yourself, you should consult an attorney, and preferably, an attorney who specializes in intellectual property rights.

1. Permission to Reprint
2. Fair Use: NOLO Press lists 5 rules to keep in mind:
  - a. Rule 1: Are You Creating Something New or Just Copying?
  - b. Rule 2:  
Are You Competing With the Source You're Copying From?

- c. Rule 3:  
Giving the Author Credit Doesn't Let You Off the Hook
  - d. Rule 4:  
The Quality of the Material Used Is as Important as the Quantity
  - e. Rule 5:  
The More You Take, the Less Fair Your Use Is Likely to Be
3. Public Domain
- a. According to [www.legaldefinitions.com](http://www.legaldefinitions.com), “public domain means that the creator of the work has given up or lost all rights to the work. It means that you may do anything with the work that you want ... read it, copy it, publish it, change it.”
  - b. Example: The words of the Star Spangled Banner are in the public domain. But *Gray's Anatomy* is another matter.
  - c. In our business, government documents, for example the 1984 Report of the Surgeon General was paid for with government dollars, and is in the public domain. If I want to reprint it, copy it, and *sell* it to you, I can!

## C. Real-Life Scenarios

### 1. Scenario #1

You are giving a lecture for a training day. To help participants better understand the anatomy of the breast—the topic you’ll teach—you want to include a copy of a drawing found in Lawrence & Lawrence’s *Breastfeeding: A guide for the medical profession*.

- a. Would it be legal for you to photocopy the page from Lawrence & Lawrence to include with your handout packet?
- b. Why or why not?
- c. What circumstances would enable you to do this, or prevent you from doing this?
- d. What else would you need to do?
- e. What does the term “fair use” mean with respect to photocopying?

### 2. Scenario #2

You attend a lecture this year where the speaker gives a lecture and handouts that look very similar to a lecture and handouts that were given last year by a different speaker. Nonetheless, you wonder if, since this is for “educational purposes” if you should do something about this or not. So what do you decide to do?

- a. Is this an ethical problem? If so, what kind?
- b. Is this a legal issue?
- c. What would you do FIRST in this situation?

### 3. Other Issues to Consider

Mark each of the following as “true” or “false.”

	1. You do not need permission to forward an article from the New York Times to an email list that you subscribe to.
	2. You do not need permission to copy an article at the library and use it to mark up and study from.
	3. You do not need permission to copy a copyrighted diagram in the handouts that you distribute to learners (for education); the only thing you need to do is cite the original source before distributing it.
	4. It’s okay to duplicate and distribute a work that you got at a conference run by the Ohio Department of Health; if the state taxpayer dollars paid for it, anyone can copy it.
	5. It’s okay to photocopy and distribute the <i>Food Guide Pyramid</i> to anyone and everyone because it is in the public domain.
	6. It’s okay to photocopy and distribute a chapter of a book as long as the chapter is going to be used in a not-for-profit organization.
	7. It’s okay to use images on the worldwide web and put them into your own presentation, because materials on the web are not copyrightable.
	8. IBLCE will take disciplinary action against IBCLCs who have violated the copyright law.
	9. You should first contact the author if you wish to reprint a work.
	10. A work does not have the © symbol on it, so you can safely assume that it is in the public domain.

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4. Legal, Ethical, and Professional Considerations
  - a. Legal Considerations
  - b. Ethical Considerations
  - c. Professional Considerations

## D. Summary

## E. Critical Resources

<http://fairuse.stanford.edu/index.html>

<http://www.nolopress.com>

## IV. Informed Consent: More than a Signed Piece of Paper

Marie Biancuzzo RN MS

Author: *Breastfeeding the Newborn: Clinical Strategies for Nurses (2<sup>nd</sup> ed.)*

### Objective

Debate whether informed consent should be obtained for common perinatal practices that have a negative impact on breastfeeding e.g., supplementation, circumcision, maternal epidural anesthesia etc. (60 minutes.)

### A. Introduction

*Con* = with, *sent* = feeling or sensing

Informed consent is “an agreement to do something or to allow something to happen, made with complete knowledge of all relevant facts, such as the risks involved or any available alternatives.” (Quote from [www.nolopress.com](http://www.nolopress.com))

Informed Consent is a two-pronged process.<sup>2</sup>

- Disclosure (provider aspect)
- Consent (client aspect)
  1. Origins and Spread of Informed Consent
    - a. Juridical Principles: Legal Impetus for Informed Consent
      - (1) In the United States
      - (2) Factors for Spread
    - b. Ethical Principles: Current Standard
      - (1) “Consent does not have so much a juridical (defensive medicine) as an ethical value. We should not, therefore, limit ourselves to seeing consent as a form of juridical protection. We should see it, rather, as a valid instrument for the defense of autonomy in decision-making and the freedom of the sick person.”<sup>33</sup>
    - c. Informed consent
      - (1) has origins in legal system, continuation as ethical imperative.
      - (2) reflects those ethical principles of beneficence, non-maleficence, veracity, autonomy, fidelity, justice, and confidentiality.
      - (3) educates client about what exactly the provider is proposing to do.
  2. When Should We Obtain Informed Consent
    - a. General Consent
      - (1) Covers general procedures one might have in the hospital.
      - (2) Signed at admission.
    - b. Special Consent

- (1) This seems to be very elusive!
- (2) Two conditions that always have special consent:
  - (a) Invasive procedure (e.g., surgery, cardiac cath)
  - (b) Legally-required (e.g., when an HIV test is performed.)
- (3) Burkhardt and Nathaniel<sup>34</sup> say, “The choice includes the right to refuse interventions or recommendations about care, and to choose from available therapeutic alternatives. This is usually discussed in relation to surgery and complex medical procedures, but also includes consent to more common interventions that may have undesirable side effects, such as immunizations and contraceptives.”

## **B. Critical Components of Informed Consent: Two Components**

1. Disclosure
  - a. Doer: Health Care Provider
  - b. What Must Be Disclosed
    - (1) Nature off the problem
    - (2) Potential risks
    - (3) Potential benefits
    - (4) Possible alternatives
2. Consent
  - a. Doer: the patient or parent or guardian
    - (1) Must be readable for client.
    - (2) Adequacy of information disclosed is based on one or more standards:
      - (a) The professional practice standard
      - (b) The reasonable person standard
      - (c) The subjective standard
  - b. "Standard" is a funny thing; hard to find a one-size-fits all standard.

## **C. Questions to Grapple With**

1. Advocacy
  - a. Do we advocate for mother’s wishes or the baby’s needs?
  - b. What happens when the mother’s wishes are different from the baby’s needs?
  - c. Informed consent for pediatric patients has unique complexities.<sup>22, 35-37</sup> And, few pediatricians have had ethics as part of their formal education, and fewer than 40% of them felt comfortable addressing less than half of the ethically-loaded issues that were posed.<sup>38</sup>
  - d. Will informed consent reduce the “unfortunate experiments” of the past?<sup>39</sup>

- e. Is informed consent enough? We may need to think in terms of moving beyond informed consent for research.<sup>40</sup>
- 2. Intervention?
  - a. Intervention may require informed consent, but what is an “intervention”?
  - b. Pilotto,<sup>33</sup> quoting the 1996 European Convention on Human Rights and Biomedicine points out article 5, "An intervention in the field of health cannot be carried out without the person involved giving his free and informed consent."
- 3. Other
  - a. Should informed consent be given prior to birth, or as part of the mother’s birth plan? Online consent has more recently emerged as a reasonable thing to do.<sup>41</sup>
  - b. Should nurses be allowed to obtain informed consent?<sup>42</sup>
  - c. Nearly all physician-trainees believe that it’s important to tell the patient if they made a mistake, but 87% listed barriers to actually revealing those mistakes!<sup>43</sup>

#### **D. How Do We Create a Special Consent Form?**

- 1. Difficulty is determining whether it is needed. AAP says, “Typically, informed, written consent is sought when there are known risks associated with a procedure or intervention.”
- 2. From the AAP's official statement on informed consent, 1995<sup>44</sup> and reaffirmed in October 2006:  
<http://www.aap.org/policy/re9850.html>
  - a. For Infant and Small Children
    - (1) Providing immunizations
    - (2) Performing invasive diagnostic testing for a congenital cardiac defect
    - (3) Beginning long-term anticonvulsant therapy to control a seizure disorder
    - (4) Initiating serial casting to correct congenital "club-foot"
    - (5) Undertaking surgical removal of a "suspicious" neck mass
  - b. AAP: Consent Needed for School-Age Children
  - c. AAP: Consent Needed for Adolescents & Young Adults
- 3. If you DO decide that a special consent form is needed:
  - a. Include the 4 key points of informed consent,
  - b. Pat Bull wrote an example in the late 1980s Pat Bull.<sup>45</sup>
  - c. AAP’s statement on circumcision was released in 1999 and reaffirmed in September of 2005:  
<http://aappolicy.aappublications.org/>

4. Advocacy
  - a. Having the client's best interests in mind. But oddly, we have a willy-nilly approach to “best interest” when resuscitating (or DNR) for neonatal and elderly patients.<sup>46</sup>
  - b. Advocacy involves helping clients to get the needed information.
  - c. Making sure they can read the information is part of advocacy.
  - d. Making sure that they understand.

### **E. Respecting, Reflecting on Culture**

- a. Attitudes, beliefs, values and practices are all related to formation of morals and ethics. Parents and providers come to health care settings with own cultural values. There’s a need for trust-generating strategies.<sup>47</sup>
- b. Social or sexual must be respond to in a non-judgmental way.
- c. We should respect and familiarize ourselves with cultural diversity, but not oversimplify what a group looks like or thinks like, or how they would choose.
- d. Misunderstandings can happen because of culture; the client’s, the family’s, the doctor’s, or those of any health care team member.
- e. Language and reading comprehension is another consideration.
- f. Informed consent is a way to help bridge the gaps that are created by culture<sup>48</sup>
- g. Barrier: Cultural relativism is the idea that “everyone is doing it.”

### **F. Evidence for Specific Cases**

1. Supplementation?
  - a. Is informed consent appropriate for supplementation? Route? Any? supplementation? For supplementation in vulnerable populations? For...what???
  - b. Cunningham’s<sup>49</sup> description of how bottle-fed babies have more disease may provide a strong basis for informed consent.
  - c. AAP says *exclusive* breastfeeding is sufficient and adequate for 6 months<sup>50</sup>
  - d. Only one consent form has been published in the professional literature, and that was over 20 years ago.<sup>45</sup>
  - e. Should we get a consent for powdered formula for preterm children, which has resulted in serious disease and even death?<sup>51</sup>

2. Epidural Anesthesia?
  - a. What is your point? What would you “disclose” if you incorporated this topic into consent?
  - b. What about informed consent for any kind of labor analgesia?<sup>52</sup>  
In 2009, the anesthesiologists in the UK supported the idea of getting a standardized card to give to all laboring women on the benefits and risks listed.<sup>53</sup>
3. Circumcision?
  - a. Howard’s study saying that feeding skills deteriorate after circumcision.<sup>54</sup>

## **G. Summary**

Although informed consent has its roots in the legal system, it has blossomed as an ethical way to promote autonomy, decrease paternalism, and promote a way to minimize the cultural barriers that may exist between providers and clients. Informed consent is a two-pronged tool that helps us better understand one another in providing general care and for specific procedures.



## V. No Easy Action: Ethical Decision-Making in Lactation

Marie Biancuzzo RN MS

Author: *Breastfeeding the Newborn: Clinical Strategies for Nurses (2<sup>nd</sup> ed.)*

### Objective

Using real-life scenarios, identify possible obstacles to ethical decisions and choose an ethical course of action. (2 hours).

#### A. Framework for Decision-Making

1. Josephson Institute Seven-Step Path to Better Decisions
  - a. Stop and think
  - b. Determine goals
  - c. Determine facts
  - d. Develop options
  - e. Consider consequences
  - f. Choose a course of action
  - g. Monitor and modify

#### B. Choosing an Ethical Course of Action

1. Selling Equipment: Who Benefits?
  - a. Conflict of interest as a potential obstacle
  - b. “I did it for you” as a potential obstacle
  - c. Using other components of the 7-step path
  - d. Choosing a course of action
2. I Disagree: Colleague Gives Wrong Information
  - a. Fear of confrontation as a potential obstacle
  - b. Using other components of the 7-step path
  - c. Choosing a course of action
3. We Always Give It: Does That Make it Okay?
  - a. “Everyone is doing it” as a potential obstacle
  - b. “If it’s necessary, it’s ethical” as a potential obstacle
  - c. Using other components of the 7-step path
  - d. Choosing a course of action

#### C. Ethical Dilemmas in Real-Life Lactation Practice

1. Panel Discussion
2. Case Studies

## **VI. Summary**

### **A. Reflections, Responsibilities, Facilitators and Barriers**

1. Ethical conduct and ethical decision-making takes reflection. You must reflect on your actions and those of your colleagues.
2. There are many facilitators and barriers to ethical conduct and ethical decision-making.
3. Your professional responsibility—and often your **legal** responsibility—is to do the right thing!

### **B. Helpful Resources**

1. Alford, C F. (2002). *Whistleblowers: Broken Lives and Organizational Power*. Cornell University Press.
2. Johnson, R.A. (2002). *Whistleblowing: When It Works—and Why*. L. Rienner Publishers

## VII. Appendices

### Appendix A: Sample of Letter Requesting to Reprint Materials

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## **Appendix B: Resources Related to the IBLCE**

### **IBLCE Scope of Practice Statement**

<http://www.iblce.org/professional-standards>

*The Scope of Practice defines the activities for which IBCLC are authorized to engage, in accord with their lactation certification. It applies to all IBCLCs, regardless of country.*

### **IBLCE Code of Ethics**

<http://www.iblce.org/professional-standards>

*The Code of Ethics sets forth the ethical principals that all certified IBCLCs and IBCLC applicants must follow and provides a guide their professional conduct. All certified IBCLCs and applicants are expected to familiarize themselves with this document, and adhere to its tenets.*

### **IBLCE Ethics Complaint Form**

<http://www.iblce.org/professional-standards>

*The IBLCE created this form so that members of the health professions, employers, clients, IBCLCs and members of the public can report incidents that may require action by the IBLCE Ethics and Discipline Committee. Signed, written complaints must be based on first-hand knowledge; details must be provided, and ethical principles that were violated must be identified.*

### **Discipline Procedures Effective 01-01**

<http://www.iblce.org/professional-standards>

*These procedures are used for disciplinary actions for applicants and those who have earned the IBCLC credential. The document explains when the IBLCE may limit, suspend or revoke credential. The document also describes the relevant authorities within IBLCE, reviews the Code of Ethics, and explains the procedure for handling ethical violations.*

## **Appendix C: Glossary of Terms**

A glossary of terms for many or most of the terms found in this handout are here:

[<http://www.ethics.org/resource/ethics-glossary>](http://www.ethics.org/resource/ethics-glossary)

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