

Informed Consent and the Intellectually Disabled Individual

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Introduction

Summary of the Case Study

Jessica is a 28 year-old intellectually disabled female with moderate to severe intellectual disability as well as multiple other medical issues. She is currently on multiple medications for this mental handicap as well as diabetes, and hypertension which includes the following: Depo Provera Injection 150 mg every 12 weeks IM, Synthroid 125 mcg daily, Neurontin 600 mg BID, Respiradol 2 mg BID, Trileptal 600 mg BID, HCTZ 50 mg each morning, Glucophage 500 mg take two tablets BID, and Prevacid 30 mg QD, as well as Calcium with Vitamin D 500 mg BID. Jessica is also on Depo Provera every three months to suppress menstrual flow and prevent pregnancy (although she most likely has not been sexually active).

On a yearly basis she is in the clinic for an annual exam and Pap smear/pelvic exam. She is accompanied by two of the staff caregivers from her long term care facility, along with 3 other patients from the care facility. She is able to interact with the staff at the long term facility by following basic commands but becomes combative when expected to do things that she does not desire or does not understand. The appointments for annual examination are made by the staff of the facility. The RN at the facility serves as the surrogate for the individuals that we see and they have control of medical decision making for the patients in this situation. The RN does not accompany the patient to be seen so actually receiving verbal confirmation of true informed consent is very difficult. Discussion regarding abnormalities, unusual findings, needed follow-up, and changes in treatment plans is usually done in writing or via telephone conversation with the RN at the facility prior to the patient leaving our office.

Jessica allows the assistant to take her weight and blood pressure. Although Jessica has allowed a partial exam (weight/blood pressure), she is undressed by her caregiver for the exam.

She is cooperative with the 1st part of the exam but refuses to cooperate for the pelvic and will not relax her legs or move down on the table. She becomes anxious and uncomfortable and begins to cry. The exam is completed without doing the pelvic exam and the patient is given her Depo Provera injection.

Current guidelines recommend pap smears and pelvic exams every 3 years. Although her surrogate for health care desires to have her do the exam and gives informed consent, the patient is refusing (by her behavior) to give informed consent. This causes conflict between what the surrogate gives informed consent for and what the patient desires. What is the best thing to do when these ideals conflict?

General Ethical Dilemma and Ethical Question

Is informed consent *Informed consent*, when the patient does not agree, even if the medical proxy desires to give consent for a procedure especially in those who are intellectually disabled?

The American Nurses Association has submitted a code of ethics that contains guidelines for the professional practice of nursing (American Nurses Association [ANA], 2001, p. 1). A fundamental principle that is expressed within this code is a respect for the inherent worth, dignity, and human rights of every individual (ANA, 2001, p. 1). This code also states that nurses must recognize the right to self-determination within the context of healthcare (ANA, 2001, p. 2). Patients also have the moral and legal right to determine what will be done with their own person and also should be involved in planning their own health care to the extent that they are able to participate (ANA, 2001, p. 3).

Lo asserts that as children grow and develop they should gradually become involved in the decision making process (, 2009, p. 267). Parents are asked to give parental permission and

children are asked to give assent (or cooperation) to medical interventions (, 2009, p. 268). During times when a child refuses to give assent and can understand what is being done and refuses it is often necessary to provide the intervention, even though the child refuses to cooperate (, 2009, p. 268). Lo also relates that forced intervention becomes more problematic with older children, less effective treatments, or more serious consequences (, 2009, p. 268).

When a provider is rendering care to a patient with intellectual disability each patient should be considered individually. Each patient has different abilities to understand and direct their own path and therefore provide informed consent. Within this context, it is important to allow the patient to be self-directed as long as this process does not compromise her overall well being. When considering this case the relationship between the surrogate and the patient the relationship is similar to the parental and adolescent relationship where the patient would give assent and the surrogate would give permission. During the process of evaluating this ethical dilemma discussed above consideration will be given to aspects of patient autonomy, informed consent, nonmaleficence, beneficence, and paternalism.

Ethics Section

Clarification and Expansion of the Ethical Dilemma

At risk groups.

There are many individuals that advanced practice nurses and other providers interact with on a daily basis which can be a source of challenge for both the provider and the patient. These high risk groups include children, expectant mothers, intellectually disabled individuals and patients who are unable to make their own decisions (Lo, 2009). Individuals with mental disability can also have differences in the amount of decision making abilities and interaction

regarding their care. Although many individuals having mild mental disability can function quite well in society and make informed decisions with guidance, those with profound mental disability are another challenge altogether.

According to the American Association of Intellectual and Developmental Disability, AAIDD, approximately 12 of 1,000 individuals or about 1.5 million Americans have intellectual disabilities (Prather & Zylstra, p. 2184). In a study funded by the National Institute of Health (NIH) in 1999, women were surveyed and approximately one-third (31%) were refused care by physicians due to their disability (Jans & Stoddard, 1999). Prather further relates that patients with intellectual disability need to be offered health screening just as it is offered to otherwise healthy adults. Guidelines regarding screening are available through several sources. Because of the trend towards deinstitutionalizing individuals with intellectual disability it is more common to care for all types of individuals within public and private settings. During this trend of more access to care within the community there are also likely to be more frequent times to provide care to these special clients (Balogh, Ouellette-Kuntz, Bourne, Lunskey, & Colantonio, 2008).

Another at-risk group that is important to consider is children. Most children have a surrogate (parent) to make medical decisions because they are unable to weigh risks and benefits, and compare alternatives and therefore cannot provide informed consent (Lo, 2009, p. 267). Lo further asserts that as children grow and develop they should gradually become involved in the decision making process (, 2009, p. 267). Parents are asked to give parental permission and children are asked to give assent (or cooperation) to medical interventions (, 2009, p. 268).

During times when a child refuses to give assent and can understand what is being done and refuses it is often necessary to provide the intervention, even though the child refuses to cooperate (, 2009, p. 268). Lo also relates that forced intervention becomes more problematic

with older children, less effective treatments, or more serious consequences (, 2009, p. 268).

When a child refuses interventions the provider should consider the seriousness of the situation, effectiveness of the treatment, reasons for refusal, parent's preferences and the difficulties in initiating the treatment according to (, 2009, p. 273). When refusals are encountered, it is appropriate to give consideration to the above findings and make the decision based on what seems most beneficial to the patient at the time. The ethical responsibility of providers caring for children which is used with the most priority is usually beneficence (, 2009, p. 276).

Autonomy

At the heart of informed consent is autonomy which means self-rule, according to Lo (2009). Lo further asserts that autonomous individuals act with intent and are informed regarding the situation. During this process they should be free from interference and control from other influences (, 2009, p. 11). He further states that individuals should be able to act with self-determination, independence, and freedom while shaping decisions regarding their personal core values (, 2009). During this process, Lo states that doctors should promote patient autonomy by disclosing information and helping the patient deliberate (, 2009, p. 11). Each patient should be treated with both compassion and respect, despite decision making capacity (, 2009, p. 11). This respect should include compassion and consideration for individual characteristics, preferences, and values (, 2009).

A patient's autonomy is generally recognized and heralded, but, not always. If a person is not capable of making informed consent, then his or her right for autonomous decision making is less important than the need to act in the patient's best interests (beneficence) (Lo, 2009, p. 11). Individuals may also be constrained if their desires for autonomy cause harm to others autonomy, harm others, or unfairly use society's resources (, 2009, p. 11).

A patient's right self-determination is also usually respected if at all possible. This is important to promote because medical care can be vastly different in intervention and goal for the same diagnosis (, 2009, p. 19). Differences in interventions and goals are usually impacted by patient, provider, and family preferences. Each intervention has the inherent possibility of risk or harm to the patient (, 2009, p. 19). This is an important consideration where the patient's own preferences should be followed if possible. Lo discusses that physicians are unable to predict patients' preferences so this should be part of the decision making process (, 2009, p. 19).

The American College of Obstetricians and Gynecologists (ACOG) discusses the ethics relating to autonomy and informed consent in their position statement that was recently revised and released ("Informed Consent", 2009). Within this position statement the ethical aspects of informed consent in obstetrics and gynecology are considered and expanded upon. One of the pertinent principles discussed was a respect for individuals and their autonomy in making decisions regarding their care ("Informed Consent", 2009, p. 1). Furthermore, this stance represents a moral right of all patients to have a right to bodily integrity, self determination regarding sexuality and reproductive health, and support of the patient within their caring relationships (, 2009, p. 1). ACOG also recommends that this respect for autonomy should be also be optimized within the overall context of beneficence while providing medical benefit to the patient while respecting them as whole individuals ("Informed Consent", 2009, p. 1).

Informed Consent

Informed consent is permission for a treatment or procedure (granted without coercion) from a competent, knowledgeable and autonomous person (Mappes & DeGrazia, 2001). Obtaining informed consent should include respect for individuals and their autonomy (Kaplan & Richman, 2006, p. 63). If a provider performs a procedure without obtaining informed consent

the provider could be charged with battery (Kaplan & Richman, 2006, p. 63). Battery is defined as an intentional unpermitted act causing harmful or offensive contact with the “person” of another (Definition of battery, 2008). For informed consent to be valid a patient must be provided with all pertinent information, participation must be voluntary and the provider should be assured that the patient is competent to make the decision being discussed (Kaplan & Richman, 2006, p. 63). In the mentally challenged individuals the capacity for them to make informed and competent decisions is also dependent on the patient and their particular situation which may vary with each circumstance (Kaplan & Richman, 2006, p. 64).

Limits to Informed Consent

Informed consent does has limitations in certain situations, such as emergencies, impaired communication or decision making capacity and the lack of a surrogate to assist in the decision making process (“Informed Consent“, 2009, p. 7). Lo further states that during situations when a patient is making an unwise decision which interferes with his or best interest (such as refusal of intubation or reversible respiratory failure), a provider may act in accordance with the patient’s best interest (, 2009, p. 12). Lo asserts that during this time a net benefit should outweigh the burdens of the intervention (, 2009, p. 12). During other times, the informed consent may be limited due to more importance being placed on another obligation such as what a person may choose may change dependent on public health concerns (“Informed Consent“, 2009, p. 8).

Voluntariness

Beauchamp discusses voluntariness is an important aspect of informed consent (Beauchamp & Childress, 2009, p. 132). In the discussion of voluntariness, he further asserts that a person is acting in a voluntary way when he or she wills the action without being held under

the control of another's influence (, 2009, p. 132). Several types of influence can be used to impact the choices of patients but the use of persuasion, coercion, and manipulation should not be used to overly influence autonomous choice(, 2009, p. 133).

Surrogate Decision Making

Surrogate decision makers are authorized to make decisions for doubtfully autonomous or non-autonomous patients by the courts in a legal decision (Beauchamp & Childress, 2009, p. 135). Surrogates make decisions in behalf of the patient based on three standards substituted judgment, pure autonomy, and in the patient's best interest (, 2009, p. 136). The substituted judgment standard allows the surrogate to state what the patient would want in this circumstance. If the question "What would the patient want in this circumstance?" can be answered by the surrogate, then the substituted judgment can then be used. The pure autonomy standard means that if the now non-autonomous person previously held a relevant, autonomous treatment preference, then this standard should be upheld (, 2009, p. 137). If the patient's preferences are not known then the surrogate can act upon the patient's best interests (, 2009, p. 138). This standard is intended to maximize the benefit to the patient in this situation. Medical providers sometimes can use this standard to validly override other's decisions such as parents of affected children, non-autonomous patients without a surrogate, and surrogates making decisions that threaten the best interest of the patient (, 2009, p. 139).

When conflict arises between the surrogate (patient decision maker) and the patient or health care provider it is important to first consider the patient. Ethics committees can also present in hospital settings and allow various individuals (both healthcare providers and public members) to debate, consider, and advise on ethical decisions when conflict arises (Jonsen, 2005, p. 44). During these debates the best-interests of involved parties, legal issues, and medical facts

are discussed while giving counsel to those involved in the conflict (, 2005, p. 45). Many times the aspects of each case can be discussed without the emotional aspects of patients, family, and provider which make discussion of the ethical facts of the case more challenging (, 2005).

Stakeholders

The primary stakeholders in this situation are Jessica, her family, and the medical surrogate. The secondary stakeholders are her providers of care which include the nurse practitioner, her primary care provider, and the staff of the facility caring for Jessica. Other stakeholders are the facility, government, and society who will absorb the cost of screening as well as the treatment for advanced disease that is not prevented by screening.

Arguments For and Against Action According to Major Ethical Theoretical Perspectives

Autonomy

According to the American Academy Of Obstetricians and Gynecologists (ACOG) providers should encourage maintenance of bodily integrity, self-determination regarding sexuality and reproductive capabilities, and provide support of the patient's freedom within caring relationships (Kaplan & Richman, 2006, p. 63). According to the above principle, the patient should be allowed to express her desires for her body and refuse the pelvic examination.

Upholding the autonomy principle is against performing the pelvic examination in this case.

Nonmaleficence:

Nonmaleficence is defined as the principle that imposes an obligation to "Above all do no harm" according to Beauchamp (, 2009, p. 149). Nonmaleficence has been a commonly used principle that is generally prima facie (one that must be fulfilled: unless it conflicts with an equal or stronger obligation) (, 2009, p. 15). Rules for nonmaleficence include: Do not kill, do not cause pain or suffering, do not incapacitate, do not cause offence, and do not deprive others of

the goods of life (, 2009, p. 153). Beauchamp further asserts that the rules of nonmaleficence are: 1. Negative prohibitions of actions. 2. Must be followed impartially. 3. Provide moral reasons for legal prohibitions of certain forms of conduct (, 2009, p. 199). *Upholding the principle of nonmaleficence is against performing the pelvic exam in this situation.*

Beneficence

Beneficence is defined as the moral obligation to act for the benefit of others (, 2009, p. 197). This includes the following rules of obligation: protect and defend the rights of others, prevent harm from occurring to others, remove conditions that will cause harm to others, help persons with disability, and rescue persons from danger (, 2009, p. 199). The relationship between a provider and a patient is fiduciary in nature, meaning that it is built on a trusting relationship between the patient and provider (, 2009, p. 32). This relationship is important because patients are vulnerable, physicians have expertise that patient's lack, and patient's rely on physicians (, 2009, p. 32). In exchange for this trust in providers, patients expect providers to act in their best interests, not in the best interests of the provider. *Upholding the principle of beneficence would be for performing the pelvic exam despite the patient wishes in this situation.*

Paternalism

The Hippocratic Oath, which guides principles of practicing physicians, also states "I will act for the benefit of the sick according to my ability and judgment (Lasagna, 1964)." A paternalistic view of medicine evolved from this oath. Paternalism is defined as intentionally overriding a person's known preferences to benefit that person (, 2009, p. 34). Paternalism is considered when the patient is at risk of significant harm and the paternalistic action will prevent the harm, when benefits outweigh the risks, the least restrictive action is taken and no reasonable alternative to the action is available (, 2009, p. 216). Previous to the era of informed consent

(prior to the early 1980's) physicians and health care providers intervened for the patient to prevent them from harming themselves due to the assumption that a patient is incapable of making a decision. This process assumes also that physicians are capable of making valid value judgments regarding patient desires just as the patient would (, 2009, p. 35). *This ethical guideline would be for performing the pelvic exam, despite the patient's wishes.*

Virtue of Caring

The virtue of caring is described as an emotional commitment to and a deep willingness to act on the behalf of those we have a significant relationship with (, 2009, p. 36). The virtue of caring is the premise of nursing and foundational to daily care we give as providers. As providers, we are obligated to give care in a compassionate way as well as show respect and guide our patients through the medical decision making process. The ways that we show caring can be varied by our approach, willingness to listen, as well as integrity within our practice. We are obligated to care for our patients and give care that is appropriate for this situation while upholding the patient's best interests. *This ethical virtue would go against performing the pelvic exam in this circumstance.*

Standard of Due Care

Standard of due care is defined as the standard of care to which all patients are due, despite their differences and disabilities. This guideline also guides a provider to not be negligent and not impose the risks of harm (, 2009, p. 153). Beauchamp also states that due care is taking sufficient and appropriate care to avoid causing harm, as determined by a reasonable and prudent person in this circumstance (, 2009, p. 153). When considering this case, there are guidelines for Pap smear collection among healthy women in the United States. These guidelines are intended to be guidelines and not absolute for each and every circumstance. According to our facility

guidelines, it is acceptable to forgo the Pap smear in low risk women if necessary. *Fulfilling this guideline would be for performing the Pap smear and pelvic exam in this case.*

Other Ways of Reasoning through the Case or Solutions

Goodness of Fit Ethic

While it is important to allow those with intellectual disability to have some form of autonomy, it is also reasonable to realize that they are a venerable population and require supervision and protection (Fisher, 2002). Goodness-of-fit ethic for informed consent is a decision making model that allows those with intellectual disabilities elicit advice from a trusted advocate during the decision making process with a compassionate provider (Fisher, 2002). This can allow the patient to have autonomy if at all possible with directed guidance from someone they trust (Fisher, 2002). This option allows for patient autonomy when possible with the assurance that the provider and the trusted healthcare advocate will both encourage the patient's best interests.

Sedation

Periodically, there will be a situation where having a pelvic exam (either by speculum or pelvic ultrasound) will be necessary in the generally uncooperative patient where a great deal of anxiety is present in the patient. During this situation a dose of a sedative such as benzodiazepine or conscious sedation is needed to assist the patient in their comfort and cooperation (Wilkinson & Cerreto, 2008, p. 217). Other techniques include relaxation, having separate visits to accommodate the patient's needs, and communication and discussion with provider's encouragement.

Avoidance of the speculum examination

A recent study was published that evaluated the use of liquid based Pap smear cytology using a speculum exam versus a blind technique (using bimanual exam) in women with developmental disabilities (Kavoussi, Smith, Ernst, & Quint, 2009, p. 115). The two groups were compared and the study found that 44-80 % of the time endocervical cells were found on the liquid based Pap smear (meaning that the Pap was done appropriately and sampled the cervix and endocervix)(Kavoussi et al., 2009, p. 115). In this study of 240 attempted Pap smears, 199 were completed and only two were abnormal (ASCUS) and the High Risk HPV tests that were done subsequently were negative (Kavoussi et al., 2009, p. 115). Rates of abnormal pap smears in this particular group are lower than the average population.

Transperineal or abdominal ultrasound

It is also important to consider that transperineal ultrasound or abdominal ultrasound may also be indicated when evaluating a gynecological issue. This is also a valid alternative for evaluating a gynecologic problem such as unexpected vaginal bleeding, dysmenorrhea, menorrhagia, or pelvic pain (Wilkinson & Cerreto, 2008, p. 217). Although ultrasound does not screen for abnormalities of the cells of the cervix, other important issues can be evaluated through creative use of these techniques.

Legal Issues

The intellectually challenged individual has been assumed to be incompetent to make autonomous decisions until just recently (Fisher, 2002). The residents of the Willowbrook State School were subjected to being injected with viral hepatitis without their knowledge and questionable consent from the patient's parents (Fisher, 2002). After this incident many people have advocated for legal rights for intellectually challenged individuals, including that the

individual is not necessarily incompetent to make decisions just because they have an intellectual disorder (Fisher, 2002). Fisher further advocates that the goodness-of-fit ethic for informed consent be followed to allow individuals to make rational, informed, and voluntary decisions with the assistance of a health care advocate (Fisher, 2002). Goodness-of-fit ethic involves the individual who has the intellectual disability to be involved in decision making while having a trusted friend or advocate with them to consider their best interests (Fisher, 2002).

There are several exceptions to informed consent, such as lack of decision making capacity, emergencies, therapeutic privilege, and waiver (, 2009, p. 25). When a patient has an intellectual disability their ability to make decisions may be dependent on the situation and complexity of the decision that needs to be made.

Women with intellectual disability are presumed competent unless that presumption has been removed by the court (Wilkinson & Cerreto, 2008, p. 220). It is also important to consider that if an adult has not had a legal surrogate named, their parents cannot make health decisions for their adult child, especially regarding sterilization (Wilkinson & Cerreto, 2008, p. 220).

Battery is the harmful or offensive touching of another person (, 2009, p. 24). Physicians or providers may commit battery if they carry out a procedure or surgery without a patient's consent or if the surgery exceeds the scope of the consent obtained preoperatively (, 2009, p. 24). Even though lack of decision making capacity can to an exception to informed consent, it is still important to consider the provision of voluntariness or assent from the patient, unless an emergency situation arises or the decision is in the best interest of the patient and there is not an acceptable alternative (, 2009). If a provider does not receive informed consent appropriately, he or she may be found negligent. To be found negligent, the provider must breach a duty to the patient, the patient must suffer harm, and the breach of duty must cause the harm (, 2009, p. 24).

Personal Decision

Throughout my time caring for women with intellectual disabilities many complex situations have evolved where correct answers are a matter of opinion. Interestingly enough, in this case I weighed the benefits and risks of the procedure against what could be lost (trust gained by this young individual) and decided how I would like to be treated if it were me. I decided to defer the pelvic exam until next year and try again. Perhaps, at some point we would have her cooperation and be able to proceed.

When evaluating the situation above, the main tenets used to promote my decision making process were nonmaleficence and the virtue of caring. Because of the nature of the situation (that this was only screening, and not an emergency or a medical issue like abnormal bleeding or pain), I was more interested in promoting this patients trust and cooperation by not performing the exam. I also considered beneficence and standard of due care when making this decision, but because the chance of abnormalities in this population is very low, it seemed appropriate to defer the pelvic exam until the patient was more comfortable and cooperative.

After looking at all of the ethical theories and informed consent in greater depth, I also still came to the same conclusion. I think that policies need to be in place for situations such as these which explain a provider's responsibilities to intellectually challenged individuals in our institution. I will also recommend further evaluation of our responsibilities to have valid informed consent each individual that we see, and have these signed by the medical proxy if the patient can't sign it themselves.

Summary

Informed consent is a challenging task among providers that we must deal with on a daily basis. When considering informed consent on the intellectually or developmentally disabled

individual, it is first important to consider the patient and their needs for care. If it is possible to allow them to make decisions without a surrogate, and they are capable then it is acceptable to proceed. If they have a medical proxy the medical proxy needs to sign consent for care to be given. It is challenging to decide who has the abilities to give informed consent and to what degree may they consent.

During the consideration of the ethics surrounding informed consent, beneficence, nonmaleficence, and the caring aspects of nursing that I employ on a daily basis it is most important to foster a sense of trust between me and the patient's I care for. This is very essential to nursing and advanced practice in general. The patient trusting your judgment and recommendations will assist the patient in being able to come and discuss problems and concerns as well as seek your assistance when problems arise. They will also be assured that your foremost priority is their safety and well-being. Although the intellectually disabled individual is not necessarily able to function normally in all aspects, building their trust is essential to their care as well.

Through weighing the ethical principles and importance of the interventions that are to be done, an intuitive provider can give compassionate care that is effective, creative, and meets the needs of both the patient and provider. At times, adjustment of the standard expectations and usual interventions need to be delayed until they can be done at a more feasible moment. When emergencies or problems arise that require intervention, the patient and provider give consideration to patient assent (because it is desired), but if necessary, and there is not acceptable alternative, the intervention is to be completed as a beneficent act (for the best interest of the patient). While providers are encouraged to act on our patient's behalf careful consideration

needs to be given to the overall needs in the clinical situation at hand to promote the wellbeing of the patient.

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Case Consultation

Worksheet A

Step 1: Personal Responses: During my current working situation, I am the provider of gynecology care for various patients. Although each person is unique and offers different aspects of complexity, the patients who are unable to communicate their desires and wishes succinctly are a challenge that I deal with on a routine basis. When the patient is unable to communicate their desires, how does informed consent impact their care and when is it truly informed consent?

Facts in the Case: Jessica is a moderately intellectually disabled female (developmentally disabled) that is age 28. She has diabetes, hypothyroidism, mental disability, anxiety, chronic hypertension, adult-onset diabetes, and acid reflux. She communicates voicing and following small simple commands. She becomes anxious when in unfamiliar surroundings. She also becomes combative when confused or forced to participate. She currently is in a long-term group home care facility in the community. She comes to the clinic with her caregiver (but not surrogate) for her annual Pap smear and pelvic exam. She is currently on Depo Provera for menstrual hygiene as well as contraceptive (although she is not likely sexually active). She is cooperative for the first part of the exam, but refuses to move down the table for the pelvic exam. She begins to cry and is not able to understand why she is being hurt. She becomes combative and refuses further examination. As her provider, the pelvic exam is deferred and the patient is allowed to get dressed.

Clinical/Psychosocial Issues Influencing the Case: As a provider in an ambulatory OB/GYN setting, routine screening guidelines are typically followed which includes a pelvic exam

on a yearly basis for most women along with pap smears on a yearly or bi-annual basis. The pelvic exam is an important screening tool to find pelvic pathology, including infection, adnexal masses (ovarian cysts, ovarian cancer), uterine pathology (fibroids), and other gynecologic abnormalities. In individuals at low risk screening guidelines can be adapted to meet individual needs. One important aspect of care in the asymptomatic individual is promotion of patient well-being and interaction with the provider so that the patient will be comfortable to seek care when abnormalities arise. It is also important to state that patients with pain, abnormal bleeding, or significant pathology require more thorough evaluation and examination than those who are asymptomatic. If the above patient had been having significant pathology at the time of the exam it would be important to act within the patient's best interests and evaluate what is possible despite the patient's discomfort.

Initial Plan: The initial plan for this patient was to defer the pelvic exam and Pap smear. I would also have the patient continue Depo Provera injections for the next year. When the patient returns for another exam, it is important to try to attempt a pelvic exam again. If significant pathology exists then sedation should be considered, as well as urine screening, ultrasound and MRI, as indicated. Alternatively, referral to a specialist who can more thoroughly evaluate the patient is also a consideration.

Policies & Ethical Code Directive: The American College of Obstetricians and Gynecologists (ACOG) discusses the ethics relating to autonomy and informed consent in their position statement that was recently revised and released ("Informed Consent", 2009). Within this position statement the ethical aspects of informed consent in obstetrics and gynecology are considered and expanded upon. One of the pertinent principles discussed was a

respect for individuals and their autonomy in making decisions regarding their care (“Informed Consent“, 2009, p. 1). Furthermore, this stance represents a moral right of all patients to have a right to bodily integrity, self determination regarding sexuality and reproductive health, and support of the patient within their caring relationships (, 2009, p. 1). ACOG also recommends that this respect for autonomy should be also be optimized within the overall context of beneficence while providing medical benefit to the patient while respecting them as whole individuals (“Informed Consent“, 2009, p. 1). Our organization allows providers to evaluate the circumstances of the medical case and make a determination for deferral of parts of the exam while using clinical decision making skills. Consultation with supervisory APN’s is available as needed by phone. Physician collaboration regarding the medical aspects of the case for unusual circumstances can also be utilized.

Ethical Principle Analysis: The ethical principles that are debated in this analysis are informed consent, respect for patients, nonmaleficence, beneficence, and a duty to provide care that is in the best interest of the patient.

Possible Legal Issues: Possible legal issues in this case include the possible claim of the patient that battery was performed by the provider. Possible legal implication: a malpractice suit from not having informed consent for care if harm to the patient should arise from treatment or omission of treatment.

Plan & Implementation Strategy: The plan for this case is to evaluate the factors that impact informed consent for those capable of informed consent. After this evaluation comparison for those who are able to give limited informed consent will be considered. Appropriate protocols and guidelines that govern care will also be utilized.

Advances Clinical/Psychosocial Interests: Clinical interests that will be given consideration

include the use of a proxy or surrogate (in absentia) to make decisions regarding care for compromised individuals. Consideration also should be given to the patient and aspects of comfort and caring that can be demonstrated by the provider.

Adheres to agency policies and professional ethics codes:

The American Nurses Association has submitted a code of ethics that contains guidelines for the professional practice of nursing (American Nurses Association [ANA], 2001, p. 1). A fundamental principle that is expressed within this code is a respect for the inherent worth, dignity, and human rights of every individual (ANA, 2001, p. 1). This code also states that nurses must recognize the right to self-determination within the context of healthcare (ANA, 2001, p. 2). Patients also have the moral and legal right to determine what will be done with their own person and also should be involved in planning their own health care to the extent that they are able to participate (ANA, 2001, p. 3).

The American College of Obstetricians and Gynecologists (“Informed Consent“, 2009, p. 3) states that the principle of respect for persons needs to be applied to each patient which states each person has inherent dignity that needs to be considered. These guidelines also include the principle that each person has a right to self determination and freedom of choice and set a personal agenda (“Informed Consent“, 2009, p. 3).

According to agency policy, each provider has the duty and responsibility to act in accordance with their own professional judgment to provide quality care for the patient that the patient desires. If a patient is unable or unwilling to give consent, then care is not

provided and alternative solutions are recommended. Consultation with supervisory and management staff are available as needed for challenging situations.

Minimizes harm and maximizes other ethical principles to the extent possible for the client and

relevant others: Plan of care include minimizing harm for decreasing stress and encouraging care for those times when the patient is experiencing a need for compassionate care at a time where symptoms of abnormalities which require intervention are necessary.

Allow you to operate within the law: According to guidelines set forth by ACOG, ANA, as well as our organization, the prescribed plan meets the needs to operate within the guidelines of the law.

Appendix BCase Study

Patient, Jennifer

DOB: 1/1/1981

DOV: 8/12/2009

Subjective/Objective: Jennifer is a 28 year old female who has a developmental intellectual disability. She is living in a group home setting with other intellectually and physically disabled individuals. She is moderately intellectually disabled and has multiple medications which she takes 1-2 times daily. She communicates by following and voicing small commands. She becomes anxious when in unfamiliar surroundings. She also becomes combative when confused or forced to participate. She has a primary care provider that manages her diabetes and hypertension. She has visits with the psychiatrist for the group home as needed for psychiatric care. She has minimal interaction with family members because they live out of state. She interacts with staff members using small commands and caring gestures. Jennifer presents to the clinic for a well woman examination. She has been weighed and had her blood pressure taken. She was undressed and changed into a gown by her caregiver (not medical surrogate) and is awaiting an exam.

Clinical Considerations:

When patients come from the group home facility to our clinic for care the information we are given on each patient is very minimal. The staff nurse at the group

home facility completes the medical history form for the patient if the patient is unable. The nurse also provides a list of medications the patient is currently taking as well as the reason for the visit (Pap, Well Woman Exam, Abnormal Bleeding, etc...). Jessica was recently placed in this group home and the nurse does not know the specifics of the patient history such as sexual history, pregnancies, gynecologic surgeries or other important aspects of the gynecologic history. The history is marked as negative as far as the nurse is aware, but this may not necessarily be accurate due to the difficulty in obtaining a valid history. The nurse then signs the medical history form and the consent for treatment for the patient. The nurse is available for consultation via phone, but it is not always obvious when the patient is capable of giving consent. The caregiver that accompanies Jessica is only providing transportation and general help in daily activities (changing, and dressing, general supervision) not medical surrogacy.

Current Medications:

1. Depo Provera Injection 150 mg IM Q 12 weeks (ongoing).
2. Synthroid 125 mcg daily
3. Neurontin 600 mg BID
4. Respiradol 2 mg BID
5. Trileptal 600 mg BID
6. HCTZ 50 mg Q am
7. Glucophage 500 mg Take 2 BID
8. Calcium with Vitamin D 500 mg BID
9. Prevacid 30 mg QD

History and Physical

Jennifer presents for a well-woman exam from a group home setting with her caregiver. She is changed and awaiting an exam. Her chart has been prepared and her caregiver presents with her. When interviewed she is unable to express sentences and answers simple commands. She is able to speak but interaction is minimal. She seems anxious even though she is cooperative with evaluation of the basic exam including her breast exam. Vital Signs: Height 4 Ft 11 Inches, Weight 211, Blood pressure 132/90, Pulse 80, Respirations 16. Her thyroid is mildly enlarged. Her breath sounds are clear and no evidence of heart murmur was found when listening to her heart sounds. Her breast exam is without masses and without nipple discharge. Axillary areas are also normal upon palpation. Her abdomen is somewhat distended due to her increased girth and she does not relax to allow adequate palpation of her abdomen. When asked to cooperate with the pelvic exam and move down the table she refuses to give assent and becomes confused and combative. The pelvic exam is then abandoned and the patient is consoled and allowed to dress. The patient is then given her Depo Provera Injection and allowed to return to the group home with her caregiver.

Plan of Care

Because Jessica is presenting for well-woman screening today and she and the caregiver relate no significant gynecologic issues, it is appropriate to continue her Depo Provera and defer the pelvic examination. As Jessica returns for care on a yearly basis or if she has gynecological problems exams should be attempted if possible. If gynecological problems arise it may be necessary to use sedation or MRI to evaluate her further. I also consulted the protocols and my supervisor regarding this situation to

discuss further indications for ongoing care despite inability to obtain a pelvic examination.

Description of Ethical Conflict

Although Jessica presents for care and appears ready for the examination to follow, her surrogate has given permission for the examination. When Jessica is examined she refuses assent (cooperation) with the pelvic exam. Even though Jessica is unable to give complete informed consent does the consent of the surrogate outweigh Jessica's refusal for a pelvic examination. What is the capability of the intellectually challenged individual to consent to examination? Is assent of the patient a mandatory part of informed consent in those who are partially able to give consent?