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## Editorial

### **Mandatory Gardasil Vaccination in Adolescents**

Biethman, E

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### **Adolescent Bariatric Surgery: A life saving procedure or another failing technique**

Blurton, B R

---

### **To Treat or Not To Treat? Cancer During Pregnancy**

Dudley, K

---

### **It's a Thin Line Between Confidentiality and Disclosing Patient Information.**

Horn, K G

---

### **Ethical Considerations of Pharmaceutical Colonialism**

Lee, A

---

### **Questioning the Persistent Vegetative State**

Medis, K J

---

### **Pediatric Advance Directives: A Voice for the Voiceless**

Nelson, H

---

### **Patient Autonomy and End-of-Life Care: Cross-Cultural Considerations**

Silvey, L

---

### **Family Presence During Resuscitation in Adult Patients**

Tafreshi, D R

---

### **Women's Self-Help Groups in India: Gender Equity, a Human Right**

Wurtz, H

---

## Editorial

Welcome to this Fifth volume of *The Journal of Undergraduate Nursing Writing*. This journal is a compilation of original articles written by senior nursing students in the Bachelor of Science in Nursing program at the University of Kansas School of Nursing.

The articles presented in this volume originated as assignments completed by students as part of their senior level coursework. The original call for papers did not limit their entries to any particular topic. All of the manuscripts received came from papers submitted in the Legal/Ethical Nursing course.

Writing about these issues was not easy. What is unique about these articles is that they provide insight into the thought processes of today's college graduates in nursing. These student authors all show an ability to describe complex societal issues in their own manner. Examples of topical choices this year include mandated Gardasil vaccinations, adolescent bariatric surgery, cancer and pregnancy, discussion about disclosure of patient information, pharmaceutical colonialism, persistent vegetative state, pediatric advance directives, patient autonomy, family presence during CPR, and women's self help groups. These students all display an ability to investigate the current evidence on their chosen topics and emerge with a unique perspective. A perspective that should encourage all of us to believe that the future of this profession is positive.

This endeavor would not have been possible without the support of several dedicated individuals and organizations. The Dykes Library staff at the University of Kansas Medical Center campus was wonderful. Delta Chapter of Sigma Theta International provided the financial support along with the positive encouragement of the Chapter Executive Board. Without this the prizes each author received for the selection of their article would not have been possible. Lastly we commend the faculty and staff at the University Of Kansas School Of Nursing for their patience and responsiveness as we sorted through all the issues necessary to make this happen. We would have been lost without their willingness to listen and share their own personal experiences.

We hope you enjoy this fifth volume and await your feedback. Let's know what you think.

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## Mandatory Gardasil Vaccination in Adolescents

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Elyse is a native of Overland Park, Kansas. While at the KU School of Nursing she participated in the School of Nursing Honors Program. She received the Arthur and Leora Peck scholarship and will graduate with distinction. After graduation she plans to start her career on the Ear/Nose/Throat/Urology Nursing Unit at KU Hospital. Her long range plans include becoming a family nurse practitioner.

Elyse works with the Coterie Theatre in the Dramatic AIDS Education program as a peer educator. In this role she works with teens whose need for knowledge help spur her to develop the content of this paper.

She wishes to thank the assistance of her mom, Margaret LoGiudice, RDH, MS and Lenn Losten, DDS, for their assistance in editing this paper.

## Introduction

The purpose of this paper is to discuss recent legislative changes about requiring mandatory vaccination of adolescents with Gardasil. In October 2006, Gardasil was approved by the Food and Drug Administration (FDA) to help prevent cervical, vaginal, and vulvar cancer caused by the Human Papilloma Virus (HPV). HPV is the virus responsible for genital warts through which are transmitted through sexual contact. The vaccine was originally intended for use in females, but is now recommended for use in males as well. Regardless of the gender of the individual, there is controversy about the need for the vaccine. The Gardasil vaccine is intended to be administered before an individual is exposed to HPV, hence young adolescents ages 11 and 12 are the targeted age group since the majority of them have yet to engage in sexual activity. Many parents, however, feel that once their child receives this vaccine that the child will then feel free to participate in sexual activities since they are “protected” from HPV. Also, there is a new issue surrounding the Gardasil vaccine’s recent addition to the Center for Disease Control’s (CDC) Childhood Immunization Schedule. Subsequently several states are pursuing legislation to require the vaccination prior to school attendance. This paper will look at the ethical issue of a state mandate requiring an adolescent to be vaccinated with Gardasil.

I choose to write about this topic because I have received the vaccine. When I was a senior in high school, the vaccine had just been approved and my parents were excited to help protect me in any way they could. However one day my mother mentioned to a coworker that her daughter was going to get “that new HPV vaccine.” The coworker not so enthusiastically replied, “Oh, my daughter won’t be needing *that*.” Regardless, I did receive the vaccine, yet controversy still exists today as to whether this vaccine is a go-ahead for adolescents to engage in sexual behaviors. Additionally, I am partial to this topic as I am a peer educator through the

Coterie Theater, teaching HIV/AIDS and sexual transmitted disease (STD) prevention to local teens in the Kansas City area. Often times I am asked by students about the vaccine, whether they should get it, and whether it is a cure. These types of questions clearly show the lack of education regarding this important new vaccine. It is imperative that the issues surrounding the Gardasil vaccine be addressed and brought to the attention of public so that adolescents can make clear, informed decisions when trying to protect themselves.

### **About HPV and the Vaccine**

According to the Centers for Disease Control and Prevention (CDC), “HPV infects approximately 20 million people in the United States with 6.2 million new cases each year,” and “cervical cancer is the second leading cancer killer of women worldwide.” In the United States, nearly “10,000 women are diagnosed with cervical cancer each year and 3,700 of these women die each year from this disease” (CDC, 2010, pg. 620). A Papanicolaou test (Pap smear) can be used to diagnose an HPV infection. It is recommended that sexually active women have an annual Pap smear exam to look for this virus and discuss other well woman issues. It is important to note that there is no cure for HPV, only treatment for related health problems.

As mentioned above, the Gardasil vaccine was approved by the FDA in October, 2006 to help “prevent four specific strains of HPV (6, 11, 16, and 18)” (McLemore, 2006, pg. 559). More importantly, “nearly 70 percent of cervical cancer cases and 90 percent of genital warts cases are linked to these four strains of HPV” (Hanson, 2010, pg. 1). Gardasil was created by the Merck Sharp & Dome pharmaceutical company as a prophylactic measure for the prevention of cervical cancer; it is not a cure for cervical cancer. The vaccine is a series of three intramuscular shots administered over six months and is targeted at “females age 11 and 12, but can be administered up to the age of 26” (Contraceptive Technology Update, 2007, pg. 32). It is a

recombinant vaccine that produces an immune response within the recipient while causing no risk of contracting the original disease, HPV. This immune response allows the recipient to produce antibodies against the four specific strains of HPV so that he or she will be able to defend against the virus if ever exposed. Additionally, as of October, 2009, the Gardasil vaccine was licensed “for use in males aged 9 through 26 years for prevention of genital warts” (CDC, 2010, pg. 620).

### **Issues**

Gardasil has been proven to be “more effective when administered prior to exposure to HPV,” which is before the initiation of sexual activity (Contraceptive Technology Update, 2008, pg. 127). Moreover, “in the U.S., sexual activity begins in ninth grade for 29.3% of girls, and 62.4% of twelfth grade girls report prior sexual activity” (Caron, Kispert, & McGrath, 2009, pg. 2). Consequently the targeted ages for both female and male recipients are ages 11 and 12. Currently, the CDC has updated the National Childhood Immunization schedule for children and adolescents to include “Gardasil, the first (HPV) vaccine...for females ages 11 to 12, and permissive use of the vaccine in females as early as age 9 and up to age 26,” (Contraceptive Technology Update, 2007, pg. 32). Given that this is the targeted age group, several states have begun requiring that young girls entering sixth grade in the public schools receive the Gardasil vaccination prior to attendance. Having a state mandate that all school girls be vaccinated against HPV has become an extremely controversial issue.

It is not unheard of for a state to require a child to receive a specific vaccination to attend school. Nearly every state mandates that school children receive most of the other vaccines in the Childhood Immunization schedule, such as those for tetanus, hepatitis B, chickenpox, and measles. The CDC creates these recommended immunization schedules so that the public may

be protect from serious, potential harm. However, it is important to take into account that never before has a vaccine been required for simply one gender of school children. School vaccination requirements are decided by state legislatures and regulatory bodies. On February 2, 2007, “Texas became the first state to enact a mandate by executive order from the governor that all females entering the sixth grade receive the vaccine;” however, “legislators in Texas passed H.B. 1098 to override the executive order” (Hanson, 2010, pg. 2). Following Texas’ actions, “19 states introduced and enacted legislation to require, fund or educate the public about the HPV Vaccine, including Colorado, Indiana, Iowa, Louisiana, Maine, Maryland, Michigan, Minnesota, Nevada, New Mexico, New York, North Carolina, North Dakota, Rhode Island, South Dakota, Texas, Utah, Virginia and Washington,” (Hanson, 2010, p. 2).

Reasons for controversy are vast, yet they center on the fact that some parents have problems giving a vaccine against an STD to adolescents. Other parents might “not want a vaccine against an STD at all, believing that their children could not be at risk, even though most reports show that half of high school students are having sex” (Iannelli, 2010, pg. 1). Still others think that Gardasil might encourage promiscuity among adolescents, since it could foster the belief that the vaccine “protects” against STDs. The reality is that Gardasil does not protect against other STDs, just HPV. Since HPV is spread through sexual contact, many parents are hesitant to talk to their adolescents about the issues surrounding this vaccine.

### **Review of Literature: Supporting**

Although the vaccine is fairly expensive, the Contraceptive Technology Update looked at the cost effectiveness of receiving the vaccine. The study took into account the cost of the vaccine, yearly Pap smear screenings, and the cost of treating cervical cancer and other illnesses targeted by the vaccine. Analysis findings indicated that “vaccination against HPV-16 and



HPV-18 would lead to lower cervical cancer rates and be economically attractive if high coverage can be achieved in the most important target group of 12-year-old girls” (Contraceptive Technology Update, 2008, p. 127). Meaning that, while the Gardasil vaccine may appear expensive to frugal consumers, it would prove beneficial to pay for one vaccine rather than spending large sums of money later in life for continuous, expensive treatments of cervical cancer. Additionally, because the Gardasil vaccine is included in the CDC’s Childhood Immunization schedule, it is available to young women 18 and younger who “are Medicaid-eligible, uninsured, American Indian or Alaska Native, or underinsured and many insurance companies are setting policy for reimbursement for the vaccine,” (Contraceptive Technology Update, 2007, pg. 32).

Concerning the administration of Gardasil, findings from a recent study of Australian teens ages 12-18 indicate that “hypersensitivity reactions to the vaccine are uncommon and most girls in this age range can tolerate subsequent doses,” yet observation for 15 minutes after administration is recommended (Contraceptive Technology Update, 2009, pg. 14). As with many other vaccines, fainting and dizziness are common side effects after receiving Gardasil and some injection site tenderness was also noted, especially after the third and final dose. Since administration of the vaccine is well tolerated, it can foster positive interactions between providers and their young female clients. Not only does Gardasil help protect young women from contracting HPV, but it also “offers family planning programs an important way to serve young girls and initiate at a very young age the discussion of the use of contraception to prevent unintended pregnancy” (Contraceptive Technology Update, 2008, pg. 127). This important conversation leads to further discussions between young women and their care providers about

the necessity of protection to prevent pregnancy and other STDs, as well as how to avoid being a victim of physical or sexual abuse.

Today, the Gardasil vaccine is approved for use in males as well as females. In males HPV generally causes genital warts, but can also be linked to certain anal, penile, and oropharyngeal cancers. Warts specifically have an adverse effect on quality of life and cost an estimated “\$200 million per year in direct medical costs” (CDC, 2010, pg. 630). The vaccination of young men is especially important considering “HPV infection in men has been shown to contribute to HPV infection and subsequent cervical disease in women,” and there is a high rate of transmission of HPV in female partners of men with pre-existing penile warts (Contraceptive Technology Update, 2009, pg. 14). More importantly, “if large numbers of girls and women do not obtain the recommended vaccinations, then vaccination of men and boys could play a significant role in lowering infection rates among males and females,” (Contraceptive Technology Update, 2009, pg. 14). Through vaccinating young men, practitioners are not only decreasing the incidence of genital warts in this population, but they are also decreasing the chance that these individuals pass HPV to their partners later in life. By applying the concept of herd immunity, where 80% of a population is vaccinated against a certain disease and thus the entire population is then considered immune, health care providers can reduce the overall occurrence of HPV infections in both males and females.

In general, the Gardasil vaccine is largely approved. A recent study noted that not only did “70.2% accept vaccination for girls,” but that after introduction to the Gardasil vaccine, “HPV awareness increased”(Christian, Christian, & Hopenhayn, 2009, pg. 439). Even organizations such as Focus on the Family and the Christian Medical Association that don't believe the vaccine should be mandatory, strongly support the vaccine itself. This may be due to

the fact that whether or not an adolescent receives the vaccine, awareness about HPV and associated risky behaviors has increased overall. Adolescents are now more aware that the actions they choose to take today may affect them for the rest of their lives. Furthermore, the most apparent and probably most obvious reason for the acceptance of the vaccine is that “Gardasil is the first vaccine that may actually prevent a cancer” (Nelson, 2007, pg. 23). With the exception of the Hep B vaccine that is targeted to prevent liver cancer, there are very few vaccines that can make this astounding claim. There is no cure for cancer, so any vaccine that can help prevent such a devastating disease is truly amazing.

### **Review of Literature: Opposing**

A significant disadvantage of the Gardasil vaccine is related to the cost. According to the Contraceptive Technology Update in 2008, the vaccine series “costs about \$360,” not including the associated costs of office visits. While the vaccine is beginning to be accepted and covered by many health insurance companies, it is still an added expense. Considering that HPV is 100% preventable through abstinence from sexual activity, many parents may not see the importance of having their child receive a vaccine such as this. Therefore, the cost alone may deter some parents from having their children vaccinated with Gardasil.

Many experts are concerned that with the protection Gardasil provides, the female population may “become apathetic about continuing regular cervical screenings,” and stop scheduling yearly Pap smears all together (Calder, 2009, pg. 20). In order for the vaccine to be effective a strong national cervical screening program must be maintained and promoted by all practitioners. To elaborate this point, “if the community is led to believe they are protected against cervical cancer and do not maintain regular cervical screenings, there may actually be an increase in the incidence of cervical cancer” (Calder, 2009, pg. 20). This issue must be in the

forefront of any medical practitioner's mind when discussing or administering the Gardasil vaccine to female clients. The individual must impart the purpose of the vaccine; that it protects against only four strains of HPV; and stress the importance of continuing yearly Pap smear exams. Practitioners must discuss the fact that engaging in unprotected sex with multiple sex partners are risk factors for contracting HPV and even individuals that have been vaccinated should refrain from these activities. Additionally when discussing the annual Pap smear, the practitioner must remind female clients that the Pap smear looks for more than just cervical cancer and can help detect other STDs and abnormalities that may also require medical attention.

Finally, questions remain about Gardasil's overall effectiveness, the duration of its protection, and possible long-term adverse effects. A "total of 10,326 adverse events following immunization [with Gardasil] were reported," with syncope and fall related injuries being the worst (Contraceptive Technology Update, 2009, pg.14). While monitoring for 15 minutes after vaccine administration is recommended, this may not always be performed or documented. Data obtained from clinical trials shows that Gardasil is "100 percent effective against [HPV] types 16 and 18," yet it is unknown how effective the vaccine is against HPV strains 6 and 11, which the vaccine also targets (Calder, 2009, pg. 20). Currently, the vaccine is expected to provide protection against HPV "for at least 20 years," but the precise extent of its effectiveness is unknown (Contraceptive Technology Update, 2008, pg. 127). A booster may be administered later in life, yet this would be another cost to parents, while again placing their adolescent at risk for potential adverse effects of the Gardasil vaccination.

### **Conclusion**

When considering Gardasil as mandatory school vaccination, we must remember that Gardasil is merely a preventative factor to contracting HPV, not a cure for cervical or other HPV

related cancers. Abstinence is still the goal for teens and young adults and should be encouraged and taught in schools. Still, there is a high chance that even if an individual waits until marriage to engage in sexual activity, that his or her partner could have or have been exposed HPV, unless it is their first time engaging in sexual intercourse, too. While parents are disgruntled about the implications of this vaccine, the fact still remains that adolescents are engaging in sexual activities and therefore it is necessary to begin vaccination at such a young age. Not only would mandatory vaccination protect adolescents later in life, but it may also protect those who are victims of sexual abuse. It is unclear if the protection that Gardasil offers against HPV will be lifelong, but similar to other vaccines a booster dose could be provided later.

This topic is extremely important to us as nurses since both medical providers and school educators need to be aware of media reporting in order to alleviate fears that the public may experience about the Gardasil vaccine. Additionally it is our responsibility to inform adolescents as well as parents about the risk factors associated with contracting HPV; the importance of maintaining yearly Pap smears; and the usefulness of the Gardasil vaccine in preventing cervical cancer. I personally have gained insight to the legislative process surrounding mandatory school vaccinations and the importance of educating all parties, not just the individual that may be receiving the vaccine. It is evident that parents and practitioners must put aside their differences and recognize that Gardasil is one of the first vaccines that may actually prevent multiple forms of a cancer. Therefore it is our duty as medical professionals and parents to do what is best for adolescents and protect them in any and every way we can.

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Adolescent Bariatric Surgery: A life saving procedure or another failing technique?

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Brooke Blurton is a native of Jetmore, Kansas. While at the KU School of Nursing, Brooke was recognized for her clinical expertise by receiving the highly coveted Clinical Excellence Award on three separate occasions (the most possible). She is a member of the Delta Chapter of Sigma Theta Tau International. She was the recipient of the Doris Geitgey and the Pusitz Nursing Scholarships. Her immediate plans are to return to a rural environment and begin practicing as a professional nurse preferably in a labor and delivery environment. Her long term goals involve furthering her education and one day attaining a doctorate in nursing education. She wishes to acknowledge the support of her fiancé, family, and Grandma Blurton for their inspiration. To God be the glory.



## **Adolescent Bariatric Surgery: a life saving procedure or another failing technique?**

Obesity is the most common nutritional disorder among adolescents in the United States (Helmrath, Brandt, & Inge 2006). The complications and sequela of obesity trickle all the way down into my own family; making this epidemic both a national and a personal concern. Lacking effective modalities to treat obesity in children puts doctors and nurses at the forefront of the ethical dilemma of saving a child's life with a risky and poorly researched bariatric surgical procedure. The following information will dive into facts known about adolescent obesity in general, alternative treatments for obesity, the ethical dilemma experienced when deciding how and when to treat a child with bariatric surgery, and finally bariatric surgery benefits and complications. Informing the reader of the trend of treating adolescent obesity with bariatric surgery and the risks and benefits associated with treatment is the purpose of this paper.

### **Obesity Epidemic**

Childhood obesity, now being classified as an epidemic in the United States, is showing a large increase in potentially life threatening associated diseases (Helmrath et al., 2006).

Body mass index (BMI) is the recommended screening tool for obesity in children. Children between the 85<sup>th</sup> and 95<sup>th</sup> percentiles are considered overweight and children above the 95<sup>th</sup> percentile are considered obese (Paoletti, 2007). The obesity epidemic taking place in America has a multi-factorial etiology including engorging in abundant, processed, and calorie dense food, leading an increasingly sedentary life style, and a genetic predisposition to being overweight (Helmrath et al., 2006).

### **Comorbidities**

Obesity is becoming a life-threatening disease not only in adults, but now increasingly in children. Helmrath, Brandt, and Inge (2006) state "A dose-response relationship between BMI during young adulthood and the risk of death has been demonstrated, with extreme obesity resulting in a reduction of 20, 13, 5, and 8 years of life expectancy for black men, white men,

white women, and black women respectively” (p. 3). Type II diabetes mellitus and insulin resistance in children has been appearing at an alarming rate. Estimates are that up to one third of all children will develop type II diabetes mellitus in their lifetime (Helmrath et al., 2006).

Atherosclerotic plaque has now been found in children as young as three years old, adding an additional problem onto the list of increasing rates of asthma, muscle and joint pain, hypertension, and sleep apnea (Ben-Sefer, Ben-Natan, & Ehrenfeld, 2009). Breast, colon, and kidney cancer have all been found at higher rates in obese adults. (Ben-Sefer et al., 2009).

Obese children are at higher risk for physical mental and social problems. Obese children engage in risk-taking behaviors, have negative body image, and lower self esteem when compared to non-obese children (Ben-Sefer et al., 2009). Health related quality of life studies found that obese children’s ratings were the same as children undergoing chemotherapy for cancer (Helmrath et al., 2006). Studies looking at long term implications of obesity give children a poorer outcome in social and academic attainment. This places them at a higher risk for mental health problems, including depression and suicide (McFadden, 2009).

### **Treatment Options**

The current ideal method of treatment in childhood and adult obesity is decreasing calories and increasing caloric expenditure through behavior modification (Berkowitz & Borchard, 2009). Predictive factors of patients who are able to keep weight off long-term, are those who eat breakfast, control food portions, monitor their weight, exercise consistently, and do not engage in binge eating (Helmrath et al., 2006). The largest problems associated with these treatments are non-compliance and lack of necessary dedication. These often lead to treatment failure of behavioral modification therapies (Berkowitz & Borchard, 2009).

Prescription mediated weight loss is another treatment commonly looked to when dealing with adult and childhood obesity. Currently, the weight loss medication treatment of choice approved for treatment of obesity in children over 16 is sibutramine, a non-selective

inhibitor of serotonin, nor epinephrine, and dopamine (Helmrath et al., 2006). This medication, when combined with a comprehensive exercise, diet, and behavior modification program has shown to increase weight loss from a placebo group norm of 2.4kg to 10.3kg (Helmrath et al., 2006). Metformin has been used safely in obese adolescents suffering from polycystic ovarian syndrome and type II diabetes mellitus. This treatment will decrease body weight and insulin resistance with moderately successful results (Helmrath et al., 2006). Although some success is documented, these methods often do not produce a large enough change in weight and are associated with multiple side effects.

### **Bariatric Qualification Guidelines**

Bariatric surgery is gaining popularity in the adult population, but is now also being performed on adolescents after multiple failed weight loss attempts. Physicians and nurses face many ethical dilemmas when families are requesting such a risky surgery (McFadden, 2009).

While the complications of obesity in children are well known, the complications of bariatric surgery are still relatively unknown. Currently there are no set guidelines directing physicians in how and when bariatric surgery is sanctioned. In 2007, the National Institutes of Health (NIH) announced that they would begin a five year observational study to assess the benefits and risks of bypass surgeries in children. This study would compare these results to adults who underwent the same procedure. They are following up to 200 children, ages 14 through 19, for 2 years following gastric bypass surgery to collect information about successes, risks, and complications of the surgery. At the conclusion, NIH will publish a set of guidelines for surgeons to follow for determining when a child qualifies for surgery (National Institutes of Health, 2007). While waiting for these risks and indications for surgery to be published, the American Pediatric Surgical Association (APSA) compiled a list of surgical guidelines (National Institutes of Health, 2007).

These indications complied by the APSA in general are much more conservative than those for adults and include comprehensive preoperative testing and postoperative follow up that assists with long term outcomes and complications (Helmrath et al., 2006). Preoperative preparation includes: identification of comorbidities, baseline lab tests, a sleep study to detect apnea, an abdominal ultrasound, and most importantly an extensive interview with a child psychologist (Helmrath et al., 2006). Part of the recommended preparation also consists of attending monthly adolescent support groups, and requiring the child to write a letter describing their indications for having bariatric surgery, long and short term complications of the surgery, dietary restrictions and expectations, and the life-long commitment required for this surgery (McFadden, 2009). The APSA stresses that the most important element of the guideline is using a multidisciplinary review board to deliberate before scheduling an adolescent for the procedure (McFadden, 2009). The type of boards recommended are only present in two United States hospitals, but have been useful in resolving controversial patient selection and treatment decisions (Helmrath et al., 2006). While awaiting published guidelines, multiple procedures are being performed without preoperative testing and adequate follow-up (National Institutes of Health, 2007).

### **Bariatric Benefits and Downfalls**

When a child is finally approved for bariatric surgery, gastric bypass is the most commonly used method. If a patient complies with postoperative diet and exercise programs patients can expect to lose 50% to 70% of excess body weight and keep it off for at least 5 years (Camden, 2009). More importantly, reversal of nearly all previously found comorbidities is documented with marked improvement in health and long term prognosis (Camden, 2009). The ultimate success of the surgery depends on the child's ability to adhere to a distinctly changed and reduced diet. This is a major source of concern because children use food choice as a way of demonstrating independence. Nutritional deficiencies are also common if vitamin and protein

supplementation and the proper diet are not rigorously followed (Camden, 2009). Early complications that develop in the weeks following surgery are found in up to 5% of the patients. These include death, gastric distention, pulmonary embolism, anastomotic leak, and wound infection. Late complications that develop after several months include marginal ulcers, abdominal pain, bowel obstructions, biliary colic, cholelithiasis, and dietary complications (Camden, 2009). Complications have been reported in up to 41% of adult patients, but complication rates in children are largely unknown (Helmrath et al., 2006).

### **Conclusion**

The most important point made by supporters of surgery is medication treatment and surgery only attempted if all other treatment modalities have failed (Paoletti, 2007). While highly controversial, bariatric surgery when studied has been the most effective treatment modality for childhood morbid obesity, but consequently also poses the largest risk (Camden, 2009). Studies of the risks and benefits of gastric bypass are currently being performed and need to be examined upon release to determine if the benefits of this uncertain surgery outweigh the risks associated, then indicators for surgery should be nationally published. Additional studies in the area of long term outcomes and consequences are crucial due to the complexity of the surgery and unique psychological and physical issues that adolescents face (Paeletti, 2007).

It is important for nurses and doctors to remember that this procedure is not a quick fix for childhood obesity. This type of surgery needs to be taken on by a multidisciplinary team in centers of expertise. As nurses, we must remember that although we do not decide the specific treatment for morbidly obese adolescents case by case, we can affect the largest proportion of people by working at the community level to provide education and physical activities for families to prevent childhood obesity. Primary prevention through physical exercise education and healthy eating techniques holds the most potential for change in the number of children suffering from obesity (Berkowitz & Borchard, 2009). Shifting from treating the individual

child to promoting health in the population will decrease health care costs long-term and reduce deadly comorbidities associated with childhood obesity (Berkowitz & Borchard, 2009).

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## To Treat or Not To Treat? Cancer During Pregnancy

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## **To Treat or Not To Treat?: Cancer During Pregnancy**

"My first thought was, what about the baby?" stated Tracy Hartman, a woman who is six weeks pregnant, after doctors told her that she had cervical cancer (University of California Davis Health System, 2010, p. 1). A diagnosis of cancer is devastating to a mother who is often overjoyed by the prospect of parenthood. Because the diagnosis of cancer during pregnancy is a relatively rare complication, 1 in 1,000 pregnancies, large-randomized-controlled trials are difficult to conduct. As a result, data is noticeably absent to support definitive treatment guidelines (Pavlidis, 2002; Pereg, Koren, & Lishner, 2008). Although there are no definitive guidelines for treatment, researchers agree that management of the disease must be patient specific (Van Calsteren et al., 2010). The purpose of this paper is to present current options for management of cancer during pregnancy and to discuss the ethical issues of beneficence, nonmaleficence and autonomy of the mother and fetus related to the treatment options.

### **Review of the Literature**

According to the Center for Disease Control, there is a rise in the rate of births to women over the age of 35 (Mathews & Hamilton, 2009). From 1970 to 2006, the proportion of first births to women over the age of 35 increased nearly eight times. In 2006, nearly 1 out of 12 first births were to women over the age of 35 (Mathews & Hamilton, 2009). The incidence of cancer in the 30 to 49 years-old age group is increasing (Van Calsteren et al., 2010). With the rates of pregnancy and cancer rising in the same population, they will inevitably collide. There will be a higher rate of cancer diagnoses in pregnant women.

The most common cancers in pregnancy are cervical, breast, and ovarian, followed by malignant melanoma, lymphoma, and leukemia (Moran, Yano, Al Zahir, & Farquharson, 2007). Cancer treatment during pregnancy is a challenge requiring the efforts of a multidisciplinary

team. There are two key concerns when considering treatment options: how the pregnancy affects the behavior of the cancer and how the cancer and its treatment affect the pregnancy (Moran et al., 2007). Therapeutic approaches to manage cancer during pregnancy include surgery, radiotherapy and chemotherapy.

Moran et al. (2007) concluded that surgery during pregnancy has been shown to be relatively safe. However, they recommend delaying non-emergent surgery until the second trimester. Waiting until the second trimester reduces the risk of fetal harm, induction of abortion and premature labor. When surgery is not an option, treatment teams may then consider radiotherapy or chemotherapy.

David Pereg et al. (2008) created a decision tree for the treatment of cancer during pregnancy. If a mother is diagnosed in the first trimester and would like to pursue radiation or chemotherapy, it is suggested that the mother consider terminating the pregnancy. During the first trimester, the fetus is undergoing organogenesis. Exposure to radiation or chemotherapy during organogenesis can result in congenital malformations, spontaneous abortions and even fetal death. First trimester exposure to chemotherapy has been associated with 10-20% risk of major malformations (Weisz, Meirrow, Schiff, & Lishner, 2004).

In the second and third trimester, the mother may consider delaying treatment until achieving fetal maturity. If treatment delay is possible, the mother will go untreated but will be followed closely by the medical team. Often physicians will perform a cesarean section or induce labor at the end of the 34<sup>th</sup> week of gestation, when fetal maturity is achieved. One study showed that 71.7% (n=129) of pregnancies were induced or had elective cesarean section at a mean gestational age of 35.6 weeks (Van Calsteren, et al., 2010). If treatment delay is not possible, chemotherapy may be administered in both trimesters. If radiation is the proposed

treatment, it is recommended that the mother terminate her pregnancy if she is in the second trimester. Radiation given 8-25 weeks after conception is associated with up to 40% risk for severe mental retardation (Otake & Schull, 1998). Radiation may be given in the third trimester after an estimation of fetal dose is calculated by a medical physicist (Pereg et al., 2008). Each of the therapeutic treatment options carries its potential complications to the mother and/or to the fetus. The potential maternal-fetal conflict raises complex ethical dilemmas.

When a pregnant female is diagnosed with cancer, her decision to treat or not treat the cancer could cause her and the treatment team moral stress. A pregnant woman with cancer will have to make life or death decisions for herself and her unborn child and it is the responsibility of the interdisciplinary treatment team to unbiasedly guide her through the treatment options (Visco, Meyer, Xi, & Brown, 2009). The mother is the major beneficiary from anti-cancer treatment; consequently, the fetus would be placed at a substantial risk for congenital malformations or death. The decision to administer chemotherapy or radiation, or to terminate the pregnancy, is indicated with a poor maternal prognosis or when cytotoxic treatment is indicated in the first trimester (Van Calstern et al., 2010). In one study, the main indication for terminating pregnancy in 29 of 30 mothers was maternal malignancy (Van Calstern et al., 2010). If the mother chooses this treatment option, the treatment team would be practicing the ethical principle of beneficence—promote good—when looking at the treatment of the mother; however, they are violating the principle of nonmaleficence—do no harm—in relation to the fetus.

The second option is to delay treatment to allow the fetus to grow, develop and become viable. By postponing medical interventions, the fetus's well-being is preserved. Delaying treatment may be harmful to the mother as it allows time for her cancer to grow and possibly

metastasize. Nettleton et al. (1996) presented a mathematical model to quantify the risk of axillary nodal metastasis as a result of delayed treatment in breast cancer during pregnancy. They calculated that there is a daily increased risk of 0.028% for tumors with moderate doubling times of 130 days and 0.057% for tumors with rapid doubling times of 65 days. If this option is chosen, then beneficence is shown to the fetus and nonmaleficence is breached with regard to the mother.

The decision to treat or not treat cancer during pregnancy includes great legal and ethical fetal rights debates (Harris, 2000). Some bioethical models assert that the health care team has an ethical obligation to the fetus as a patient, because the health care team can care for it medically (Harris, 2000; Harris & Paltrow, 2003). An ethical paper outlines two criteria that, when met, does not violate nonmaleficence or beneficence obligations to the fetus. The beneficence-based obligation to the fetus has reached its limits if there is (1) a certainty or very high probability of a correct diagnosis, and (2) either certainty or a very high probability of death or severe irreversible deficit of cognitive developmental capacity as a result of the diagnosis (Chervenak & McCullough, 2009). Even when an ethical obligation exists, they do not have equal weight to legal obligations (Harris & Paltrow, 2003). Numerous court decisions have concluded that neither fetal rights nor state interests on behalf of the fetus supersede a woman's autonomy or rights as the ultimate medical decision maker (Harris & Paltrow, 2003).

The most important of the ethical principles to uphold in this situation is the mother's autonomy (Harris & Paltrow, 2003). To respect a patient's self-determination, a physician must provide patients with evidenced-based clinical information that allows the mother to make a competent decision. The health care team must provide nondirective counseling as to not suggest or imply a recommendation (Chervenak & McCullough, 2009). A mother's decision on

her course of treatment or lack of treatment should be her own. Attempting to bias a woman's treatment decision violates her autonomy. Respect for the mother's autonomy includes respecting her treatment decisions, even if they are in conflict with the health care provider's moral beliefs.

### **Conclusion**

It is my opinion there will be two areas of nursing practice that will see the impact of cancer during pregnancy – oncology nursing and obstetric nursing. Oncology nurses will see a rise in pregnant patients and obstetric nurses will see a rise in oncology patients because these patients are one in the same. A rise in cancer during pregnancy will require that nurses become cross-disciplinary. With cross-disciplinary training, the nurse will be better equipped to handle this delicate situation. A nurse who is educated in both obstetrics and oncology will be able to provide answers to questions that are unique to a patient who is battling cancer while being pregnant.

Until new medications are established or the safety of current treatments on a fetus is solidly established, the nursing community must be aware of the treatment decisions that must be made. With any of the treatment options, the health care team could be faced with an ethical dilemma. Does the health care team uphold the principles of beneficence to the mother by treating the cancer, while simultaneously violating nonmaleficence toward the fetus? Or, does the health care team show beneficence to the fetus by not exposing it to harmful anti-cancer treatments and risk placing the mother in harm's way? The nurse will have his or her own opinions on what course of treatment a mother should choose; however, it is important to remember the nurse's role is to serve a patient advocate. Deciding on a course of treatment will not come with ease; however, it is one that will have to be made by the mother.

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## It's a Thin Line Between Confidentiality and Disclosing Patient Information

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### About the Author:

Kerri Horn is from Torrance California yet has called Lawrence Kansas home since 1997. She is the recipient of the Level III Clinical Excellence Award from the University Of Kansas School Of Nursing. Her future goals are to specialize in mental health after developing a well rounded medical surgical knowledge base.

She acknowledges that she did not start college until she was 21. Early in her career her younger brother developed an ear infection that infected his brain. A month later her mother's life was saved when she developed a hole in her colon requiring immediate surgery and extensive follow up. The care provided to both of her relatives was provided by KU Hospital in Kansas City, Kansas. It was these experiences that caused her to refocus her life and seek a career in nursing.

She wishes to acknowledge her mentor in nursing school, Dr. Kathleen Brewer, and Professor Mary Meyer for their positive influences, Cyndie Schudel for her continual guidance and support both before and during nursing school, and her classmates for their amazing support during all the ups and downs of college.



## **It's a Thin Line Between Confidentiality and Disclosing Patient Information.**

### **Introduction**

There is a fine line between maintaining confidentiality and sharing patient information in the healthcare profession. The purpose of this paper is to discuss the importance of maintaining confidentiality, as well as, discussing why it is crucial in some situations to disclose or share patient information. Confidentiality is among the eight ethical elements important to nurses. Maintaining confidentiality is important because of trust. The patient must know they can trust the healthcare team, as the majority of the information provided is very personal and private. If a patient does not trust their doctor/nurse they are likely to omit certain details of their life that may be very useful in treating their illness.

Due to the nature of the nurse-patient relationship the law seeks to protect the patients' right to confidentiality. The court considers inappropriate disclosure of health information to be detrimental to the patient and may be considered a tortuous breach of confidentiality (Beech, 2007). Various acts put in place to protect patient information will be presented to explain the importance of maintaining confidentiality, identifying the importance of disclosing patient information, and the exceptions.

### **Review of Literature**

Confidentiality is a crucial part of the healthcare. It is a legal obligation and part of the duty to care to a patient (Beech, 2007). There are many ways the nurse may maintain patients' health information. Making sure to only disclose necessary information to healthcare team members is justified (Griffith, 2008). The nurse must be certain that patient information is not visible by anyone who does not have permission to view. For example, locking electronic devices or logging off the patients' information is not accessible. When talking to a patient or

other healthcare providers, it is essential to make certain that no one else can hear the conversation. This may be done by talking in a private room or by being aware of how loudly you are speaking. Many times as healthcare providers forget little things that can also be considered a breach in confidentiality, or the patient's right to privacy.

Confidentiality is not only a legal element for nurses but a law that is found in common principles. The Data Protection Act of 1998 began in 2000. It replaced previous legislation and includes all social services and health records. "The act requires that all data are processed fairly, legally and accurately, and that information is held for no longer than necessary" (Beech, 2007, p. 42). This includes collecting, processing, storing, and the transferring electronic and manually held data (Edwards, 2009). Patients also have the right to read their health records if they wish to do so, as the information belongs to them. The Freedom of Information Act 2000 was created to address information held by public authorities. The information of concern in the Freedom of Information Act is recorded information to allow statistics be used to improve patient outcomes. This law works separately from the Data Protection Act 1998 that exempts personal information from being used.

Unfortunately the legal obligation to maintain confidentiality is not absolute (Beech, 2007). There also is no absolute requirement for healthcare staff to disclose or not disclose information to the police which is stated under the Police and Criminal Evidence Act 1984 (Beech, 2007). This act does not include information in connection with crimes that involve terrorism, and certain sections of the Road and Traffic Act 1999 requiring the identification of people involved in accidents (Beech, 2007). The National Health Service provides guidance about assisting police with the prevention or detection of serious crimes such as murder, rape and kidnapping and allows disclosure of this information (Beech, 2007).

Minimal guidance is provided to nurses and healthcare professionals on exactly when it is considered justifiable to disclose patient information. In general the law requires that patients provide consent when disclosing information. The best form of consent occurs when the patient gives consent or is provided exactly what information will be disclosed and to whom. Explicit consent is required when the information will be used for non-health related issues, sharing with other agencies or with relatives. It is important to note that information that is already considered public knowledge is not said to be a breach in confidence (Cornock, 2009). It is also good practice that the nurse does not give a blanket statement assuring confidentiality, but rather explains that the information provided will remain confidential unless someone is at risk or a serious crime has been committed (Edwards, 2009).

In healthcare confidentiality is placed at a very high level of importance and for that reason there are very few exceptions to override a person's right to confidentiality, therefore it is important that the nurse is aware of the exceptions that allow disclosure of patient information (Fullbrook, 2007). Appropriate disclosure is a necessity for effective care and for the protection of vulnerable patients, while also avoiding any allegation of misconduct or breach in confidentiality (Griffith, 2008). One very good example is in the situation where a fifteen year old girl confided in a nurse advising that she had recently been raped. About three weeks after telling the nurse the young girl committed suicide. Due to the fact that the nurse gave her word to keep this information confidential, she did not report the incidence to police. In this situation the nurse would have been justified in breaching confidentiality. The nurse should have discussed the situation further with the patient to try and persuade the patient to seek out help and to contact the proper authorities. If the patient was unwilling to do so, it then would have

been the nurse's legal obligation to contact the police because to protect the welfare of children and vulnerable populations outweighs the duty to maintain confidentiality (Griffith, 2008).

Disclosure in the interest of justice, public good, protection of a third party, and to prevent or detect a serious crime are all exceptions that cover a broad range of situations in which confidentiality should not be maintained. *The Nursing and Midwifery Council (NMC) Code of Professional Conduct: Standards for Conduct, Performance and Ethics* (NMC 2004) states that each registered nurse, midwife, or health visitor must report to the appropriate person any circumstance that jeopardizes safe standards of practice or any circumstance in which safe and appropriate care cannot be provided to the patient (Beech, 2007). Public safety is also considered extremely important and may be a reason to override confidentiality (Fullbrook, 2007). Due to the fact that healthcare providers have a duty to care for their patients as well as causing no harm, confidentiality sometimes must be broken in order to protect the patients overall well being.

Patients disclose private and personal information because they believe that the information will be used for their benefit. Keeping information confidential is for the benefit of the individual as well as society (Cornock, 2009). Court order, statutory duty, public interest, informed consent or anonymization is the only legal reasons why confidential information can be given to secondary users. Unless disclosure is mandatory or consent has been given the legal reasons provide justification for a breach in confidentiality. The preferable way of sharing grouped National Health Service (NHS) information is done through anonymization. This replaces the need for consent and also changes the information so that it is not considered personal information, as all patient identifiers have been removed, thus this removes the legal requirement of data protection (Harris, 2009).

If the nurse or healthcare provider is unsure whether to share patient information for any reason they can contact a Caldicott Guardian. The Caldicott Guardian helps to ensure that the NHS upholds the highest standards for handling patient identifiable information. “The Guardian will actively support work to facilitate and enable lawful and ethical information sharing” (Griffith, p. 120, 2008).

### **Nursing Implications**

Overall, confidentiality must be maintained by the nurse and healthcare providers in most situations. The nurse must assess all aspects of care, making sure to only disclose information to the necessary parties. Nurses have the duty to care for their patients and provide safe, ethical care. As stated previously the nurse must evaluate whether the patient is at risk or in immediate harm. Also the nurse must assess whether the matter is a concern for public safety.

### **Conclusion/Summary**

Nurses and healthcare providers should use their common sense, experience, and ‘gut’ feelings to evaluate whether information should be shared. In obvious situations where patient or public safety is a concern or even a risk the nurse should at the very least notify their immediate supervisor and follow up on the decision that was made. After researching this topic it has reiterated to me how important patient confidentiality is. Also knowing the exact laws and exceptions to disclosing patient information helps guide the nurse. Confidentiality is like one of many aspects of nursing in which the nurse must take a macroscopic approach and look at the whole picture before disclosing patient information.

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## Ethical Considerations of Pharmaceutical Colonialism

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Alexandra Lee is a native of Prairie Village, Kansas. While at the KU School of Nursing she obtained an Endowment Scholarship. Her scholarship achievements are recognized by receiving the Golden Key award. She is a member of Delta Chapter-Sigma Theta Tau International. Her future plans include becoming a neonatal nurse practitioner. While at the KU SON she was selected to travel to Johannesburg, South Africa where she participated in providing nursing care to the countries citizens. Alexandra wishes to recognize the support she has received from her family, especially her mother and father, in supporting her through her nursing and college education

## **Introduction**

The complexity of the ethical issue being depicted is one that has transcended generations, bringing light to issues such as human rights, distributive justice, and the worldly effects of globalization. The subject termed ‘pharmaceutical colonialism’ is in part characterized by the colonization of developing countries in efforts of contributing to the sphere of pharmaceutical knowledge. The purpose of this descriptive essay is to enhance the readers knowledge of ethical considerations of importance to nursing regarding the conduct of clinical trials in developing countries. The significance of comprehending pharmaceutical colonialism is due to the gravity that the subject has on human rights globally. The human rights that are at greatest concern of being breached in medical testing include autonomy, nonmaleficence, respect for persons, and veracity. Considering that human rights do not only pertain to medical personnel, but to all persons globally, preserving the sanctity of these rights is imperative to continuation of the livelihood of each individual.

### **Nigerian Lawsuit Uncovers Modern Day Pharmaceutical Colonialism**

During the past decade, the country of Nigeria filed a lawsuit against the North American drug company, Pfizer. This lawsuit was brought forward because research antibiotics were given to Nigerian children. The antibiotic in question is called Trovan, a medication that was approved by the Federal Drug Administration for adult use only under specific circumstances that included beginning therapy in health care settings and with treatment lasting no longer than 14 days (CNN, 1999). Due to Trovan’s aggressive nature on fighting bacterial infections, Pfizer was anticipating a gross worth of \$1 billion per year from its administration (Stephens, 2007). However, claims of extensive liver damage in adults were reported by use of Trovan, and the Federal Drug Administration restricted the use of the medication in 1999 (Stephens, 2007).



Meanwhile, an epidemic of meningitis was occurring in Nigeria and neighboring countries, causing countless deaths. In response, Pfizer conducted a clinical trial for the administration of Trovan and its hypothesized effectiveness in treating pediatric meningitis (Stephens, 2007). However, Trovan had never been approved for pediatric uses by the US Federal Drug Administration (FDA). The medication was administered in field hospital settings, in Kano, Nigeria. During the same time as Pfizer's clinical trial, Doctors without Borders were dispensing approved antibiotics, and, according to a Nigerian study, "Trovan had a survival rate that was at least as effective as the best treatment available at Kano's Infectious Disease Hospital" (Hladky, 2010, p. 2). Stephens reported that eleven children died during the experiment and 189 suffered blindness, deafness, and severe mental disabilities (2007).

Soon after Pfizer's claims of Trovan's survival rates, reports surfaced accusing Pfizer of fraudulent documents and inadequate consents pertaining to the study's methods. This was confirmed by the lead researcher, Abdulhamid Dutse, who admitted to forging letters after the experiment. Furthermore the Nigerian ethics committee never gave its consent to Pfizer to administer Trovan to pediatric patients (Stephens, 2007). Dutse stated that he, "then backdated the letter to March 28, 1996—a week before Pfizer's experiment began" (Stephens, 2007, p. 3). It has also been alleged that Pfizer failed to inform families of Trovan's side effects, and that a medical group, Doctors Without Borders, was concurrently administering "a conventional and effective treatment" free of charge at the same hospital (Richey, 2010, p. 3). The lawsuits also bring into question whether the physicians, during the clinical trial, administered high enough doses of the approved antibiotic to the children in the control group (Hladky, 2010).

Pfizer claims that the efforts by the Nigerian government to support claims that they mislead the country or families of Nigeria in any way is false. Pfizer goes on to state that the

company's intent "was to bring a life saving, innovative, and cost-effective form of antibiotics that could be used effectively in a meningitis epidemic in the developing country" (2007, p. 1). However, many others believe that Pfizer conducted the experiment and took advantage of the vulnerability of a country unable to defend its people from nonconsensual clinical trials. This was done to promote Western pharmaceutical expansion, and that this type of clinical trial would not have occurred with American children (Richey, 2010).

The United States Supreme Court allowed Nigerian families to sue Pfizer under the premise of the Alien Tort Statute, allowing for the trial to take place in the United States. Prior to this current lawsuit, the state of Nigeria brought legal claims against Pfizer from the damages during the clinical trial. Reports are that this claim was settled for \$75 million. In part of the settled amount, Pfizer had agreed to grant a trust fund for the families and children involved in the lawsuit estimating at \$35 million of the \$75 million (Hladky, 2010, p. 4). However, "the Nigerian government's cases were not brought on behalf of those trial subjects and do not resolve Nigerian families' claims in the U.S. lawsuit" (Bollyky, 2009, p. 3).

### **Nursing Implications of Pharmaceutical Colonialism**

One of the most relevant nursing implications of this ethically, controversial issue is that of cultural awareness. It is critical for nurses to be informed not only about the health care in their own country, but health care policies, or lack thereof, in other countries. Nursing as a profession treats people from a variety of cultural backgrounds, and for nurses to be considered culturally competent the profession must have an understanding of health issues in other countries.

The ineffectiveness of producing informed consents appears to be a consistent sub-issue of pharmaceutical colonialism. The definition of informed consent pertains to two

parts: that the participation is done voluntarily and that the participant is informed in entirety (Guido, 2010). Informed consent, even though the process has been established both nationally and internationally, still presents obstacles to researchers (Marshall, 2007). The participant's understanding is a key feature of informed consent, and even so, comprehension has posed various obstacles in ensuring adequate informed consent due to medical jargon and complicated experimental protocols (Marshall, 2007). For example, an HIV vertical transmission study, target population of South African women, found that even though consent was voluntary, many of the women participated in the study because they believed that they were not allowed to resign their participation, or that their child would therefore receive no prophylactic care (Marshall, 2007). Patricia Marshall noted that in order to ensure a participant's understanding of the informed consent process, that there should exist a process of testing the informed consent to ensure its ability of comprehensiveness before the recruitment development commencement (2007).

### **Conclusion**

As a result, it is our duty as nurses to be aware of the cultural differences that may arise when presenting a document of informed consent to the patient, and to allow for any interventions, such as a translator, to be present in order to ensure that the patient not only understands the procedure, but also alternative treatments, side effects, and expected outcomes. Thus, in essence, being a patient advocate.

The accepted definition of nonmaleficence is to do no harm. The condition is not whether a clinical trial originated out of deceit or humanitarianism, the far more crucial concept is the applicability of that clinical trial to its target population, and the beneficial or harmful effects a trial has on that target population. Chippaux states that,

Only drugs that meet Africa's needs should be tested there. They should satisfy specific criteria determined by their potential use. They should be effective and, in given the inadequacy of local mechanisms to monitor side effects, harmless. They should be accessible, and easy to distribute, prescribe, and administer. They should... encourage the patient adherence to treatment, compensating for weakness in the health system (2005, p. 4).

Therefore, the immoral fault that lays with Pfizer is the African children's deaths contributed by an antibiotic whose optimistic purpose was to save the lives of American children. To quote John le Carre's screenplay, *The Constant Gardener*, there are "only regrettable deaths [in Africa]. And from those deaths we derive the benefits of civilization, benefits we can afford so easily... because those lives were bought so cheaply" (2005).

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Questioning the Persistent Vegetative State

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## **Questioning the Persistent Vegetative State**

This paper concerns the topic of the Persistent Vegetative State (PVS) and some of the ethical dilemmas surrounding it. PVS is defined as a “condition in which the patient is wakeful but devoid of conscious content, without cognitive or affective mental function” (Smeltzer, Bare, Hinkle, & Cheever, 2010, p. 1857). This is an important subject to nurses as they are called to be advocates for patients and endeavor to “do no harm.”

### **Review of Literature**

The PVS term was developed in 1972 by two doctors, Jennett and Plum, because of the increasing number of brain damaged patients surviving trauma in a state that was not comatose and appeared irrecoverable (Jennett, & Plum, 1972). Most recently PVS has been amended by the Multi-Society Task Force and the Royal College of Physicians in 2003 to include characteristics of a patient with a sleep-awake pattern, responding to stimulation only in a reflex manner, and showing no meaningful response to the environment; considered awake but not aware (Royal College of Physicians Working Group, 2003).

Although diagnostic criteria can be somewhat universal, as seen by the two previous definitions, professional organizations differ in specifics. Some may use bowel or bladder incontinence as part of their criteria while others completely omit it (Borthwick, & Crossley, 2004). Differentiation in criteria can be problematic with regards to diagnosis and misdiagnosis. Although Jennett goes on to state that recovery from PVS is rare and exceptional, studies show that misdiagnoses is notable, varying from 17% to 75% (as cited in Borthwick et al., 2004).

The prevalence of PVS in the United States is 46-100 per million people (Jennett, 2002). Because of low incident rates, physician exposure to clients with PVS is disproportionate indicating a lack of expertise particularly in diagnosis (Borthwick et al., 2004). “Even those



clinicians who see a number of such patients are rarely responsible for, or trained in, the longer term management of brain damaged people” (Andrews, Murphy, Munday, Littlewood, 1996, p.4). This brings into question who *is* qualified to determine a diagnosis of a vegetative state.

Diagnosis of a vegetative state takes substantial skill, should be regularly assessment over a considerable length of time, and must never independently determined by a physician from the bedside. The rationale is that a multidisciplinary approach must be used including those with expertise in the care and management of clients with complex disabilities (Andrews et al., 1996). Family accounts must also be sincerely considered. It is usually other members of the multidisciplinary team such as occupational therapists and psychologists that determine “awareness” in clients and ultimately communicate this with the physician (Royal College of Physicians Working Group, 2003). It is critical to understand, though, that the physician is the final determinant of the diagnosis and ultimately, of referral to courts for removal of nutrition or hydration (Andrews et al., 1996).

Cognition or awareness can be determined by eliciting responses to simple commands through pressing buzzers, eye pointing, or motor responses such as finger, arm, shoulder, or head movements (Andrews et al., 1996). Therapists are aware, though, that clients are affected by a multitude of factors including fatigue, general health, contractures, medications, and underlying conditions, which can alter responses making them inconsistent (Borthwick et al., 2004). In a study conducted by Andrews et al. (1996), all of the misdiagnosed patients were actually severely disabled, 65% being either blind or severely visually impaired, making motor and visual responses difficult to impossible (Andrews et al., 1996). Positioning is imperative for appropriate motor responses and clients may need rehabilitation to achieve an optimal state to even elicit a response. Stress is a factor to consider as the patient is mandated to respond to stimuli in order to

prove his awareness (Borthwick et al., 2004). Depression, as well, could substantially inhibit a patient's motivation to interact due to his perception that he is being treated like a "vegetable" (Shewmom, 2004).

The terminal patient may be someone dying from renal failure or cancer. As he nears death, he often refuses nutrition and hydration. This is believed to be a normal, natural, and painless progression towards death as the patient submits to his underlying medical condition (Smith, 2003). The question lies, though, in the nature of the person diagnosed with PVS. Is this patient terminal? Is this patient dying? The PVS patient suffers from a failing brain which inhibits the ability to eat. The digestive tract is intact and functional, able to absorb and use nutrients (Truog, 2005). The lack of food and water for this patient could be the cause of death, a death by dehydration and starvation.

St. Louis neurologist, William Burke, states that the cognitively disabled person removed from nutrition and hydration suffers from dehydration. As his mucous membranes dry out, his skin, tongue, and lips crack. He suffers from nose bleeds. His stomach lining dries out and he suffers in agony from the pangs of hunger and thirst (as cited in Smith, 2003).

Kate Adamson suffered from an incapacitating and debilitating stroke at the age of 33. She was misdiagnosed with PVS and eventually her feeding tube was removed per court order. She suffered eight days without nutrition or hydration before her feeding tube was reinserted. She described those eight days as, "sheer torture" ("She recovered from," 2003, p. 1).

Jennett refers to disabled patients as a burden to the health care system, a waste of care better spent on those who are more deserving (Jennett, 1976). Ronald Cranford's editorial in the British Medical Journal states that the severely handicapped state is of more abhorrence to most

people than the possibility of being in a state of persistent vegetation and might even be considered a greater impetus behind ceasing nutrition than PVS itself (Cranford, 1996)!

From this utilitarian perspective, the human person is defined by strictly functional criteria: consciousness, for example, with the rational and motor capacities necessary to make decisions and take action. These are criteria of social utility, derived from a philosophical position that places function above being. The simple fact that one exists is no longer sufficient for that individual to qualify as a person, worthy of respect and legal protection. That individual must be able to think and act rationally and be endowed with the capacity to contribute actively and positively to social life. Otherwise, the argument goes, society has no obligation whatsoever to assume the financial and psychological burdens that a profoundly handicapped person imposes on it. (Breck, & Breck, 2005, pp. 136)

These views, which may be prevalent, are not universal. Many believe that the human person is to be valued because he is inherently sacred and valuable regardless of his physical or mental health.

Even the most severely disabled and helpless patients retain the full dignity of human personhood, justifying the provision of nutrition and hydration which, “should be considered ordinary, proportionate, and morally obligatory” (Baumgartner, 2006, para. 3). It is essential that patients unable to orally consume food should receive nutrition and hydration including those in persistent vegetative states. This moral obligation may at times become devoid as in cases where the patient approaches inevitable death and prolonging life would be exceedingly burdensome causing discomfort (United States Conference of Catholic Bishops, 1996).

## **Conclusion**

The patient in a vegetative state is at risk for being misdiagnosed or treated by a doctor with little expertise in dealing with brain damaged people. Vegetative states are difficult to diagnose and take the teamwork of all disciplines. Even with a correct diagnosis, PVS patients with severe physical disabilities are worthy of treatment including nutrition and hydration.

The primary loyalty of the nurse is to the patient. We are expected to be advocates especially to vulnerable populations. Patients have the right to self determination but those in persistent vegetative states may be vulnerable to the wishes of their surrogates or medical providers in the case of misdiagnosis. Nurses, being the closest healthcare provider to the patient, can offer enlightenment and information that other members of a multidisciplinary team cannot. It is pertinent for nurses to become more informed about these issues and to educate others. They can participate in ethics committees at their institutions of employment or within the community. Ultimately, it may be impossible for nurses to intervene in situations where surrogates or providers are making decisions with which they do not agree. In these situations, they are not obligated to participate in practices that encourage compromise of personal beliefs. They can be true to their moral and legal convictions and if needed, refuse to engage in unethical situations.

As a future nurse, I approached this topic with some preconceived ideas about PVS and the ethical issues surrounding it. Through research, my view became further solidified. I found information that was much more varied than I anticipated including the topic of inadequate care to the disabled, which I find alarming yet fascinating. I definitely feel that my knowledge of PVS has been expanded and that I can speak on this subject with increased confidence.

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Pediatric Advance Directives: A Voice for the Voiceless

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Heather Nelson is from Spring Hill, Kansas. While at the KU School of Nursing Heather received the Visiting Nurse Association Scholarship for 2010. For 2011 she received the Hagen Student Opportunity Award, the Sara Patterson Award, and was a nominee for the KUMC Student Leadership Award. Her clinical excellence was recognized with an honorable mention for the coveted Clinical Medical Surgical Excellence in 2010. In 2011 she received the equally prestigious Level III Clinical Excellence Award for her work during her critical care clinical. After graduation she plans to start her professional nursing career in the Medical Intensive Care Unit at the University of Kansas Hospital.

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## **Pediatric advance directives: A voice for the voiceless**

### **Introduction**

You have been hospitalized over four times during the previous year in an Intensive Care Unit (ICU), intubated and placed on a ventilator for pneumonia and respiratory distress. You have grown up living with a chronic condition that has deprived you of oxygen, left you with an inability to properly digest foods and little hope of a reproductive future. Daily life involves swallowing 21 different pills, hours of nebulizer treatments, and chest physiotherapy. You have become close to other children who also suffer from this chronic, debilitating disease to watch them die a slow, agonizing death as they starve for air. You are acutely aware that this is your fate, and you want some control over your otherwise powerless circumstance. You are 15 years old with end-stage Cystic Fibrosis and you are ready to die with dignity.

However, your parents have something else in mind. Today you were admitted, once again, to the ICU in increased respiratory distress becoming disoriented as your carbon dioxide levels soared. Your parents have insisted, against your expressed wishes, that everything medically possible be done for you. In accordance with their wishes, you are sedated, intubated, and placed on a ventilator. This is the story of C.G. (Dickey & Deatrck, 2000). It could be your story, the story of your child, or any one of the more than 3,000 adolescents in the United States that die annually from the effects of a chronic illness (Freyer, 2004).

Chronic, terminal illness is a reality that all nurses working in pediatric settings are faced with at some point their careers. When the child is too young to make decisions regarding health care treatments, the decision easily becomes that of their parents and is supported by the healthcare team—but what about the more mature adolescent? Whose decisions do we legally and ethically support as nurses caring for these patients and their families? The purpose of this

paper is to examine adolescents' ability to make competent decisions, and explore the legal and ethical ramifications surrounding the use of Pediatric Advance Directives.

### **Review of Literature**

As defined by Collins English Dictionary (2010), the word competent involves “having suitable or sufficient *skill, knowledge, experience*, etc., for some purpose” (para. 1). There is growing support among respected pediatric health care professionals that adolescents who suffer from chronic, incurable illness through their *experience* possess the *knowledge* required for competency regarding the consequences of deciding to withdrawal life-sustaining care. Nine years of research by Bluebond-Langner (as cited in Freyer, 2004, p. 382) culminated in the conclusion that “dying children reach an understanding of their own impending deaths as the cumulative result of personal experiences with serious illness and medical treatment.” These children have spent an exorbitant amount of time in the hospital, endured countless medical treatments, and have first hand experience coping with the adverse effects associated with those treatments. They have bonded with other children in the hospital setting with similar conditions and watched those friends succumb to the battle of medical futility. These experiences have provided “multiple opportunities to think about the inescapable suffering that characterizes their lives, the features of life that make it worth continuing, the benefits and burdens that accompany medical treatment and the prospect of death” (Weir & Peters, 1997, p. 33). Evidence strongly supports that adolescents living with terminal illness meet the definition of competency in regards to making health care decisions, including the decision to forego medical treatments that merely extend their pain and suffering and prolong their inevitable death—but where does the law stand?

Federal law has long recognized individuals who meet the definition of legal competency as having the right of autonomy, known as patient self-determination in the health care setting (Guido, 2010). For more than 35 years, the United States has defined legal competency as achieving the age of majority, identified as age eighteen (Freyer, 2004). For individuals younger than 18 years old medical decisions, with few exceptions, are deferred to their legal guardian(s).

At the state level, adolescents may seek health care without prior consent from their parents in limited, very specific circumstances when it is believed requiring prior parental consent would result in these individuals not seeking treatment. Examples include treatment for sexually transmitted diseases, pregnancy and pregnancy prevention, alcohol and drug abuse, and in some states, psychiatric illness (Weir & Peters, 1997). Withdrawing life-sustaining care is not one of these circumstances.

The Mature Minor Doctrine is a common-law rule that allows an adolescent to plead their case for competency regarding health care decision making through a judicial hearing on a case-by-case basis (Freyer, 2004). The challenge of the Mature Minor Doctrine is that chronically ill children are often too weak to make petitioning their case in front of a judge plausible. Without support from their guardian(s), they also—by virtue of their age—have limited access to the necessary transportation to travel to court. In addition, the Mature Minor Doctrine is not recognized by all states. Over one-half of all states have no specific mandate to ensure protection for competent minors desiring to make end-of-life care decisions, leaving little autonomy for the vast majority of dying adolescents (Freyer, 2004).

On a national level, congress enacted the Patient Self-Determination Act in 1990 with the goal of protecting patient autonomy at the end of life through the creation of advance directives (Zinner, 2009). This act has been a guiding force in resolving potential legal and

ethical issues surrounding end-of-life care for adults but is not recognized for persons under the age of eighteen. Legal governance—both at the state and federal level—stops short of granting minors authority to make decisions that would ultimately result in their death, giving rise to ethical deliberations.

Ethical debates about pediatric advance directives are well documented, yet argumentatively divided. Weir and Deters (1997) propose that healthy adolescent development is characterized by growing autonomy, fostered by the individual assuming an increasingly active role in determining their future. Chronic, incurable illness cripples developing adolescents with a loss of control over their future, which diminishes their sense of autonomy. Ross (1997) cautions granting decisional authority to adolescents arguing that permitting them the right to autonomy in the present deprives them of having authority in the future. The author makes the case by asking if one should allow a child with Type I Diabetes to refuse insulin shots because they fear needles, provided they understand that the consequence for not taking insulin would result in their death. Freyer (2004) counters Ross by stating that in the case of terminal illness there is no prospect for long-term autonomy. Future autonomy is reserved for otherwise healthy teenagers who are expected to recover from acute illness, as would be the case in Ross's scenario. Immediate autonomy is the only autonomy relevant to the dying teen.

Zinner (2009) contends that the importance of autonomy is strongest near the end of life. Giving these individuals a voice through pediatric advance directives may promote peace by empowering autonomy as death becomes inevitable. In addition, advance directives may offer peace of mind to parents. Discussing and determining in advance what treatments are to be done promotes assurance that they are fulfilling their child's wishes in the final days of life. By working in collaboration with their child, the feelings of guilt and doubt—traditionally

associated with having to determine whether and when to shift the goal of care from cure to comfort—are lessened. Lyon et al. (2009) found that “family-centered advance care planning by trained facilitators increased congruence in adolescent/surrogate preferences for end-of-life care, decreased decisional conflict, and enhanced communication quality” (p. e199).

Physicians and nurses may also benefit from the advent of pediatric advance directives. In the same way that adult advance directives have increased assurance to healthcare providers, pediatric advance directives would also provide clear guidance that they are acting in accordance with the patient’s wishes and respecting their autonomy (Weir & Peters, 1997). Having documentation of the patient’s expressed wishes provides the healthcare team direction in their plan of care and lends support during palliative care consultations with the family, allowing the healthcare team to return to the true priority of their care—the patient.

### **Conclusion**

Provision 1.4 of the American Nurses Association (ANA) Code of Ethics (2001) states that “patients have the moral and legal right to determine what will be done with their own person; to accept, refuse or terminate treatment without deceit, undue influence, duress, coercion, or penalty” (p. 4). Autonomy is a fundamental nursing virtue, which we assert to uphold. There is tremendous evidence in support of adolescents’ competency regarding health care decision-making, especially those who have lived for months, or even years, with a chronic, incurable illness. In light of this evidence, there appears to be lag, or hesitation, on the part of the legal system to make definitive statutes about granting competent minors the right of self-determination when those decisions may result in the termination of their life.

Provision 3 of the ANA Code of Ethics (2001) states that “the nurse promotes, advocates for, and strives to protect the health, safety, and rights of the patient” (p. 6). As nurses, it is our

duty to advocate for our patients' autonomy. We can collaborate with families to provide care for their dying loved one in a way that is respectful of their wishes and avoid the turmoil lived by adolescents such as C.G. Nurses can be instrumental in becoming a voice for these voiceless minors by advocating at the bedside with families, and at the systems level for change in the current Patient Self-Determination Act to include advance directives for competent adolescents.

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Patient Autonomy and End-of-Life Care: Cross-Cultural Considerations

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Linus Silvey is from Overland Park, Kansas. While at the KU School of Nursing he received a KU Endowment scholarship for the 2009-2010 and the 2010-2011 academic year. He was a member of the University of Kansas Honor roll for the 2009-2010 and the 2010-2011 academic year. He also received the prestigious Clinical Excellence Level III Award for his outstanding performance in the critical care clinical area. Following graduation he will become a member of the Medical ICU professional nursing staff at the University of Kansas Hospital. His future plans are to pursue a career in intensive care nursing with a long term goal of becoming a nursing educator.

## **Patient Autonomy and End-of-Life Care: Cross-Cultural Considerations**

### **Introduction**

The purpose of this paper is to describe the influence of culture and religion on end-of-life decision making and advance care planning. Over the last few decades there has been increasing amounts of attention and controversy on end-of-life planning. Highly publicized North American cases such as Karen Quinlan and Nancy Cruzan have brought the topic of patient's rights to refuse unwanted treatment into the limelight. This public debate of end-of-life treatment paved the way for federal legislation. One such piece of legislation is the enactment of the Patient Self-Determination Act of 1990. It requires health care facilities to provide information about advance directives to patients at the time of admission (Guido, 2010, p. 181). Recently there has been a growing interest in cultural and religious influences on end-of-life planning. Members of the multidisciplinary team need to be aware of the practices in different religions and cultures regarding end-of-life care. The United States is becoming increasingly more culturally diverse, including increased diversity between members of the health care team. As of 2001, literature on end-of-life care had only begun to investigate the related cultural differences on the matter (Kagawa-Singer & Blackhall, 2001).

End-of-life decision making is an important topic for me because I plan on pursuing a career in critical care nursing. Nurses in critical care units frequently encounter patients from a variety of cultures and religions who are in their end stages of life. During my critical care rotation, I observed an ethical dilemma relating to end-of-life care. An adult patient in my unit was admitted following a motor vehicle accident. The patient was unconscious upon admission and was in need of a blood transfusion. The parents of the patient would not allow a blood transfusion to be done due to their religious beliefs. At the time I was shocked to hear that a

parent would choose to withhold life-saving treatments, even after hearing that it may result in the patient's death. I also wondered if the patient held the same belief system as the parents however, there was no advance directive. This incident validated the importance of advance directives and encouraged me to explore the decision-making processes people from different cultures have in advance care planning.

### **Review of the Literature**

In the United States, patient autonomy is the primary focus of ethical decision making in health care regarding end-of-life planning (Johnstone, & Kanitsaki, 2009). This holds true in the Australian, Canadian, and United Kingdom health care systems where autonomy is seen as empowering and has been the moral bases of end-of-life decision making. Johnstone & Kanitsaki, (2009) note that individuals from Greek, Chinese, and Ethiopians cultures do not regard autonomy as empowering. Groups such as these view autonomy as isolating and burdensome to patients who are sick and too uniformed about their condition to make reasonable choices.

In some cultures patient autonomy may not be a valued ethical element in end-of-life planning but seen primarily as a duty of the family. They believe it is the family who has the responsibility to protect the dying patient from the burden of making difficult choices about medical care (Kagawa-Singer & Blackhall, 2001). In the qualitative study by Kwak and Salmon (2007) there was a general agreement between the Korean-American participants that the cultural expectation is for the family to make the final end-of-life decision. Medical professionals who insist on patient autonomy for end-of-life decision making, without taking into consideration the patients cultural perspectives, could be seen as paternalistic and hostile (Johnstone & Kanitsaki, 2009).

In the cases where consent cannot be obtained, the end-of-life decision is usually left in the hands of the patient's proxy or the health care team. This poses a problem with patient autonomy. In an example where the patient and the patient's family are Jehovah's Witnesses, a life-saving blood transfusion may be refused for the patient due to religious beliefs. The health care professional may feel that denying this patient a blood transfusion goes against their ethical principal of non-maleficence and beneficence, yet respecting the family's decision deals with autonomy (Cartwright, 2000).

Veracity is another valued ethical element that is part of the American Nurses Association (ANA) professional code of ethics (Guido, 2010, p. 15). Certain cultures have different view points on what should be disclosed to the patient for end-of-life planning. In the Chinese culture the family has the primary responsibility to care for the patient, especially in times of severe illness. In their culture, not disclosing information to the patient about their illness and prognosis can be viewed as a way of protecting them (Kirsch, 2009). In the study by Blackhall, Murphy, Frank, Michel, and Azen (1995), a sample of 200 Korean-American subjects were surveyed asking whether they favored the physician disclosing information regarding a terminal prognosis. The results of the study showed that 65% of the participants said that they believe the patient should not be told their terminal prognosis.

Kagawa-Singer and Blackhall (2001) described that often a patient will request to not directly receive information from a healthcare provider about the terminal nature of their illness. They further described that this does not mean that this information can be provided through other communication means such as nonverbally, or indirectly. This is a common practice in some Far East Asian cultures and the Japanese term for this is "inshi denshin" which literally translates to "knowing without being told". Some clinicians have developed strategies to handle

situations where the patient does not want to be informed and it is referred to as “informed refusal” (Kagawa-Singer & Blackhall, 2001). Informed refusal is similar to a durable power of attorney, for health care purposes. Informed refusal is when the patient designates someone to receive all medical information and make health care related decisions on their behalf. Medical professionals need to make sure they do not stereotype various cultures, such as assuming a Chinese woman would not want to be told her diagnosis because she is Chinese. That is why it is important for the medical professional to take culture seriously and attempt to understand cultural differences by assessing a patient’s health care values and beliefs (Kagawa-Singer & Blackhall, 2001).

Lack of advance directives and communication is the bases for much of the distress that occurs during end-of-life planning (Kirsch, 2009). In cases where patient autonomy is the priority of the family, utilization of a durable power of attorney for health care decisions may allow the patient to use their autonomy to appoint a surrogate to decide health care based decisions. There are many barriers to patients participating in advance care planning. Research reviewed by Johnstone and Kanitsaki (2009) suggests:

Patients of minority cultural and language backgrounds are fearful that if they complete advance care plans and advance directives in a mainstream health care context, they may be left to die in instances where further medical intervention could improve their health outcomes. (p. 408)

Johnstone and Kanitsaki (2009) concluded that empirical studies exploring cross-cultural differences in end-of-life decision making consistently show that advance directives and advance care plans are less frequently completed in people of minority cultural backgrounds compared with the majoritarian population. In the qualitative study done by Kwak and Salmon (2007), a

majority of the elderly Korean-Americans and caregivers that were interviewed had no knowledge of or had misconceptions about end-of-life care. The main misconception was the inability to reverse decisions made in their advance directives (Kwak & Salmon, 2007). Kwak and Salmon (2007) found that “Many of the caregivers also expressed that it was ultimately the family’s decision, but all caregivers wished that their parents would complete an advance directive to guide them in making decisions” (p. 1869).

### **Conclusion**

Nurses along with other health care professionals have a fundamental responsibility to assist patients and family with the end-of-life decision making process. Being culturally competent is more than having a basic understanding of different cultural norms. It is more the interaction with the patients and their families to better understand their needs and values that is needed. It has been shown that culture plays an important role in a person’s perception of health and the health care decisions they make (Kagawa-Singer & Blackhall, 2001). One of the things I learned from researching for this project is that culture can play a significant role in the choices patients make in regards to healthcare. It also reiterates the importance of cultural competence in health care by being able to effectively assess the influence that a patients culture has on their end-of –life decision making process. Obtaining and then using his information would help ensure the presence of adequate communication resources for non Caucasian population.

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## Family Presence During Resuscitation in Adult Patients

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Legal/Ethical Foundations for Professional Nursing Practice

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A native of Overland Park, Kansas, David expects to start his nursing career as a member of the Neurological Intensive Care Unit at the University of Kansas Hospital after graduation. His future plans include pursuing graduate work in nursing and eventually becoming involved in community education and health promotion. "Too many health programs are being cut in grade schools and it is our responsibility to get out and help the community." David follows his two sisters Azita and Paresa as KU School of Nursing graduates. He wishes to acknowledge the support and love of his mother Sharon Tafreshi. "Without her constant presence we could never have made it through the grueling program at the KU School of Nursing."



## **Family Presence During Resuscitation in Adult Patients**

### **Introduction**

In the hospital setting, there are few moments that are as intense as the events that take place when trying to save an arresting patient's life. Physicians and nurses are working briskly - if not frantically - shouting orders, performing rib-cracking compressions on the patient's chest, administering life-saving medications, and jolting hundreds of joules of electricity into the patient's body. Yet family presence during resuscitation efforts has become an important and controversial ethical issue in health care settings. Families are requesting permission to witness such events. Members of the health care team are split on this issue, noting benefits but also potentially adverse consequences to family presence during resuscitation efforts. As nurses, it is our responsibility to find the delicate balance between what is best for the patient, the family, and the institution. The purpose of this paper is to present an objective exploration of the ethical dilemma of family presence during resuscitation in adult patients from the perspectives of each of the key players — the family, the patient, and members of the health care team.

### **Literature Review**

#### **Family Perspective**

Evidence currently indicates that family members would prefer to be present during cardiopulmonary resuscitation (Benjamin, Holger, & Carr, 2004). In 1998, Barratt & Wallis administered a 6-question survey to family members who lost a loved one after cardiopulmonary resuscitation. Four of the 35 (11%) respondents were actually offered the opportunity to be present during the resuscitation effort; 24 of 35 (69%) indicated they would have liked the opportunity to be present, and 15 of 29 (62%) indicated they would have preferred to be present during resuscitation. In a similar study by Meyers, Eichhorn, & Guzzetta (1998), nurses

conducted interviews with families who had recently had a family member die in the emergency department. When asked if they would have liked to have been “brought into the room during CPR”, 20 of 25 (80%) said “yes”. In response to whether or not they would have liked the opportunity to be present, 24 of 25 (96%) said “yes”. Finally, when asked whether the family thought presence during resuscitation would have helped with the grief from the death, 16 of 25 (68%) said “yes”. During the interview a number of family members also voiced that they thought it was their right to be present and that the option should have been offered.

The above studies also attempted to investigate what family members believed happened during resuscitation. The responses were mixed and perceptions of resuscitation were often inaccurate. In the study by Barratt & Wallis (1998), family members were offered space on the survey in which to write what they believed occurs when the healthcare team tries to save someone’s life during a code. Responses ranged from “electric shocks” to “no idea” (Barratt & Wallis, 1998, p. 110). Meyers et al (1998) during the phone interviews, one family member indicated that TV programs had shown her what cardiopulmonary resuscitation was like, and she “did not think it would be too much to handle” (p. 403).

An investigation to examine the effect on families who had been present during a loved one’s resuscitation in which the family member died revealed that every participant would, given a second chance, choose to witness the resuscitation effort again (Robinson, Mackenzie-Ross, Hewson, Egleston, & Prevost, 1998). The benefits from witnessing the emergency procedure included an opportunity to see the family member a final time, the ability to see that efforts were made to save the loved one’s life, and a feeling of closure. This investigation also addressed the possibility of negative, long-term psychological effects. The findings revealed that none of the

participants had any significant results, such as increased anxiety or depression, as a result of witnessing the resuscitation effort (Robinson et al., 1998).

### **Health Care Staff Perspective**

Despite a lack of evidence of psychological trauma from families witnessing resuscitation efforts, members of the health care team have certain misgivings regarding family presence. In a study conducted by Helmer, Smith, Dort, Shapiro, & Katan (2000), members of the Emergency Nurses Association (ENA) and the American Association for Surgery and Trauma (AAST) were surveyed to gauge nurses' and physicians' beliefs regarding family presence during resuscitation. When asked whether or not family presence was a patient right, ENA members were significantly more likely to respond "yes" than were AAST members. Additionally, there were significantly more AAST members who believed family presence would cause interference with procedures. Even though the groups differed on a number of subjects, both agreed that family presence would increase stress during a resuscitation effort. Members who had actually been present during a resuscitation effort with family present were asked to rate the overall experience as positive or negative. The majority of the AAST respondents (75%) classified the experience as negative; on the other hand, 64% of ENA members found it to be positive (Helmer et al., 2000).

A randomized control study conducted by Fernandez, Compton, Jones, & Velilla (2009), examined the effect of family member presence on physician performance during a code. The study design used simulated medical codes and three different "family member" scenarios — no family member present, quiet family member present, or hysterical family member present. The amount of time it took the physician to start CPR, intubate, and announce a time of death were similar in each of the scenarios. However, when the hysterical family member was present, it

took longer for the physician to defibrillate the patient, and fewer shocks were administered once defibrillation occurred. Upon completion of the simulation, physicians were asked what concerns they had when the family members were present during resuscitation. Common responses included worries about an increased amount of time to complete a procedure due to family interference, family well-being, and apprehension about an increased potential for litigation (Fernandez et al., 2009).

### **Patient Perspective**

At times during the course of these debates, it seems that the perspectives of the people at the center of the issue — the patients themselves — are overlooked. One investigation by Benjamin, Holger, & Carr (2004), attempted to understand what a sample of emergency department patients felt would be appropriate if they were ever to require cardiopulmonary resuscitation. The investigation began by educating the 200 study participants about what exactly happens during cardiopulmonary resuscitation. The ED patients were then asked if they would like to have a family member present during resuscitation. The majority (72%) indicated they would like to have a family member present during resuscitation. Those who did not want family present cited a fear of family members interfering with the procedure or that it may leave a negative final memory of them (Benjamin et al., 2004).

### **Conclusion**

The literature indicates that there is quite a difference in opinion among family, health care staff, and patients when it comes to whether or not families should be present during resuscitation. Most family members not only want to be present but believe it is their right, and the right of the patient, to decide. Physicians believe that family presence may interfere with the procedure itself, that it could increase the chance of a lawsuit, and that it certainly increases

stress during a code. They also believe that because of the intensity of the event that it may be traumatic for family members to witness. Although nurses seem to be more receptive to the idea of family members being present during resuscitation, this group has misgivings about how witnessing this process may lead to an increased level of personal and family stress.

Part of what makes this issue an ethical dilemma is that there are both potential benefits and potential consequences to family presence during a code. Additional research needs to be conducted regarding the perspectives of the members of the health care team in order to either validate their concerns or to emphasize the need for educational efforts aimed at discrediting inaccurate assumptions. Either way, nurses have an obligation to treat both the patient and the family; thus, it is especially important for them to be receptive to, and advocate for, the family's desires. If family presence ultimately is found to have negative outcomes for the patient, then the family may need to be excluded. However, denying family members access to a resuscitation effort simply because of health care staff opinion is a paternalistic idea that needs to be abandoned. Upon completion of necessary research, institutional policies may have to change to give family members the choice on whether or not they want to be present. However, due to the virtues of autonomy and confidentiality, it should ultimately be the patient's decision.

As a nursing student, formulating a concrete opinion on this issue is somewhat difficult because I have yet to experience a resuscitation effort in practice. Nevertheless, as I continue to accrue new clinical experiences, and especially after conducting this literature review, I am able to thoughtfully consider and acknowledge the valid perspectives of each of the parties involved. This insight will be crucial because I plan to work in an ICU, where encountering this exact ethical dilemma is inevitable.

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## Women's Self-Help Groups in India: Gender Equity, a Human Right

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### About the author:

Heather Wurtz is a native of Topeka, Kansas. She is the recipient of the Level II Clinical Excellence Award from the KU School of Nursing for her clinical excellence in the pediatrics setting. She is an honors graduate from the School of Nursing. She is the recipient of the Helen Crilly, James D. Robinson, George and Margaret Varnes, and Marguerite Coffman Nursing Scholarships. She was also awarded a Shawnee County Medical Society Alliance Scholarship and received a Delta Chapter-Sigma Theta Tau travel award to present her honors research. Her ambitions for the future include pursuing dual graduate degrees in Public Health Nursing and Public health with a concentration in maternal Child Health. Eventually she sees herself as a nurse researcher focusing on maternal child health in the global arena.

She wishes to acknowledge the faculty, staff, students and patients at the Christian Medical College of Vellore, India for sharing their experiences, stories and lives with us when we traveled there for her professional practicum experience.

## **Women's Self-Help Groups in India: Gender Equity, a Human Right**

### **Introduction**

“Human development is an expansion of the real freedoms of people to pursue lives that they value and have reason to value” (UNDP, 2010, p. 85). Throughout the world, gender inequality—pervasive and deeply embedded in societal structures and ideologies—continues to inhibit human potential and retard the social and economic development of individuals, families, and entire populations. Viewed by many as an abuse of basic human rights, gender inequality perpetuates negative outcomes of health and well-being, and propagates undemocratic, unjust, and unproductive social patterns and political processes. Yet, despite these negative effects, gender inequality still exists—for many, to a devastating degree—in the daily lives of women in most parts of the world (Sen, 2004). Regional patterns of reproductive health—the greatest indicator of gender inequality (UNDP, 2010)—reveal that “the equivalent of five jumbo jets’ worth of women die in labor each day”<sup>i</sup> (Kritsof & WuDunn, 2009, p.98). Ninety-nine percent of these mortalities occur in developing countries (WHO, 2007).

India, a country vastly plagued by the ill effects of gender inequality, accounts for nearly 1/5 of total maternal deaths globally and only trails behind Sub-Sahara Africa for total losses due to reproductive health disparities (UNDP, 2010). According to the United Nations Human Development Report of 2010, India ranked 118 out of 138 countries, according to the gender equality index<sup>ii</sup>. Statistics demonstrate incredibly poor outcomes for women in India in nearly all indicators including health, education, economics, and political participation (UNDAF, 2000). In efforts to ameliorate these critical disparities, India has established Women's Self-Help Group (SHG) programs into their national plan as a keystone of development efforts to improve economic and social circumstances of women through grassroots microenterprise and group



solidarity. The impact of SHG's in India has the potential to contribute to the empowerment of women, as well as improved health for women, their families, and possibly subsequent generations.

The purpose of this article is to briefly describe the effects of SHG—within an Indian context—on the overall health of women, in order to grasp an understanding of this debated public health paradigm and to consider its applicability to a diversity of settings. As members of an increasingly globalized health care community, it is imperative that nurses and other health care professionals exercise a 'global frame of reference' by evaluating major global healthcare issues and emerging trends of respondent actions by authoritative international agencies (Austin, 2001, p. 1).

### **Review of Literature**

In the 1990's, SHG's become a popular development strategy in India to alleviate poverty and empower women after the renown success of the Bangladeshi project, the Grameen Bank. The founder of the Grameen Bank, Muhammad Yunus, went on to receive a Nobel Peace Prize in 2006, for his achievements in microfinance (Nobelprize.org, 2011). The basic premise of the Grameen Bank and similarly modeled SHG's entails the attainment of economic autonomy and social capital by impoverished peoples through a peer-lending, microenterprise banking approach. "From the very outset the Bank was designed to be owned and controlled by the people who borrow from it (Jansen & Pippard, 1998, p. 109). In more recent years, SHG's have been considered a successful method of improving healthcare access and outcomes (ICDDR, 2001). A conference organized by a conglomerate of international health organizations, including three international Red Cross societies, United Nations Development Program, and

Plan International, "revealed renewed interest in self help, viewing it as a cost effective and sustainable approach to social development, especially health (Nayar, 2004, p. 6).

Women's SHG's are voluntary associations, generally consisting of 12-20 people from a similar background that engage in micro-lending through shared monetary savings and group accountability in efforts to generate income, reduce poverty, and participate in the local economy (Mohindra, 2008). Each member of the SHG contributes a small weekly deposit into a shared group savings account at a commercial bank. At the group's discretion, members may apply to receive a loan, which can then be applied towards economic activity or significant budgetary constraints. In addition to material assistance, SHG's provide emotional support and community building; "they are frequently cause-oriented, and promulgate an ideology or values through which members may attain an enhanced sense of identity" (Katz, 1981). Members attend weekly meetings at where, in many cases, various relevant health issues will be discussed (Nayar, Kyobutungi, & Razum, 2004). Participants may also be involved in skills building sessions and/or leadership training (Jansen & Pippard, 1998).

SHG's have frequently been reported to help reduce poverty and increase participation in the work force among impoverished groups of women (Larance, 2001; Reddy & Manak, 2005). Further studies, however, have also demonstrated that SHG's may serve as a significant tool of empowerment via women's increased participation in community action, political affairs, and household decision-making. In Tesoriero's study among SHG's in Southern India, 72% of SHG member were involved in community building activities; 67% participated in the local village council; 56% were part of social action programs (2005). Leaders of SHG's are often asked to attend and speak at local village meetings (Reddy & Manak, 2005). "It serves to show how, from the women's perspectives, identifies have changed in relation to their position in their

families and communities, from being oppressed towards active engagement as citizens in their village and Panchyat (council)” (Tesoriero, 2005, p. 329).

Additional studies have revealed that SHG's in India positively affect the psychological health of poor women. According to a study by Mohindra, women in SHG's were less likely to report emotional stress and poor life satisfaction (2008). Furthermore, it was found that among SHG members, emotional stress declined with increased membership duration (2008). In another study, by Rajandran & Raya, over 94% of participants who were SHG's members reported increased courage, self-confidence, and empowerment due to their involvement (2010).

SHG's have also been found to yield more direct positive health outcomes. Women in SHG's are able to borrow loans to cover costly health expenditures, thereby preventing exclusion from necessary health care services (Nayar, 2004; Mohindra, 2008). Even women who are not participants themselves but who live with SHG participants may experience less exclusion from healthcare services (Mohindra, 2008). Although SHG originally focused primarily on economic activities, several groups are now integrating health campaigns and health education into their regular activities (Nayar, 2004). Weekly meetings provide opportunities for women, to discuss issues related to nutrition, immunizations, hygiene, and maternal child health care (Gov. of Kerala, 2011). Several studies from Bangladesh reinforce positive health outcomes related to SHG's by describing increased knowledge of health, increased disease prevention, and decreased rates of domestic violence among SHG members (Hadi, 2002; Bhuiya, Hanifi, Hossain, & Aziz, 2000).

A large literature suggests that in addition to the individual benefits of SHG participation, the overall improved status of women may foster improved health for the entire family, especially regarding child health and nutrition (Angrist, 2002; Chiappori, Fortin, & Lacroix,

2002; Duflo, 2005). Throughout the developing world, maternal malnutrition is a primary cause of low birth weight in infants (Ramakrishnan, 2004)—which can be a source of a myriad of additional complications, even into adulthood<sup>iii</sup>-- by improving the health of women, positive health outcomes for subsequent generations will also likely increase. Children's health may also improve when women have more control of household finances and decision-making. Women tend to prioritize health needs over other expenditures and “are less likely to squander funds” (Jansen and Pippard, 1998, p. 111). “It is argued that women invest the money in goods and services that improve the well-being of families, in goods that are conducive to development” (Duflo, 2005, p. 12).

### **Conclusion**

SHG's has become a major strategy in India for combating gender inequality through a holistic approach to health and well-being. It is estimated that in 2005, over 2 million SHG's had been established throughout the country (Reddy & Manak, 2005). Although the sustainability of poverty reduction measures has been questioned in recent years (Kumar, 2007), the impact on other avenues of health in the lives of participants has been exhaustively demonstrated—especially in the testimonies of SHG members. “While a range of sources of data has contributed to building a picture of change and transformation, none has been so powerful as the stories of the women themselves” (Tesoriero, 2005, p. 327).

Gender inequality, within India and on a global scale, has become a pressing issue that requires aggressive and definitive action. The Millennium Development Goals for 2015, adopted by 189 countries, has prioritized the reduction of gender inequality as a key objective. In order to achieve this international endeavor, partnerships and mutual understandings must be established at the national level, but must be executed in the local arena by local leaders. Nurses

throughout the world have a unique opportunity to contribute to this cause. Nurses are on the forefront of social and community change action; nurse's all-encompassing approach to health and ability to engage women in the community, allow them to facilitate health improvement as a development tool. The many 'faces of gender inequality' (Sen, 2004) must not be obscured by contextual or cultural differences; they must be viewed through the lens of these differences in order to realize their common threads. Issues that may seem quite foreign at first glance, may, in fact, not be so far from home and ultimately, from a global mindset, "the health threats faced by any one country are ultimately faced by all countries" (Huston, 2008, p.3-4). Through awareness of global issues and reactionary interventions, nurses can better understand these challenges within their own cultural context and may do their part to contribute to a brighter future in their own communities and, consequently, throughout the world.

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<sup>i</sup> In 2005, 536,000 maternal deaths occurred worldwide (WHO 2007)

<sup>ii</sup> The Gender Inequality Index reflects inequality within three primary dimensions: reproductive health, empowerment and the labor market. "The Gender Inequality Index is designed to reveal the extent to which national human development achievements are eroded by gender inequality, and to provide empirical foundations for policy analysis and advocacy efforts"(UNDP, 2010).

<sup>iii</sup> Recent findings have shown that low birth weight may contribute to higher incidence of hypertension, glucose intolerance, and other cardiovascular problems (Barker, 2006).