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Update

Volume 17, Number 3 (March, 2002)

Celebrating our contributors: Convocation, 2001

Note from the theological co-director:

For eighteen years the Center for Christian Bioethics has operated with distinction because of the generosity of those who support our work. Once again, we take note of this support and offer thanks. We appreciate those who donated to our yearly operating budget. We appreciate those who volunteered their time and energy to conducting the work of the Center. We appreciate those who built upon the endowments established that secure our future operations.

In this issue we not only list our contributors for the year 2001, we also publish articles from two of our students currently in the MA in biomedical and clinical ethics program. Both of these women have distinguished themselves within their fields of dentistry and nursing and presented the following works at our most recent (November, 2001) annual Contributor's Convocation in Desert Palms. Georgina Manning, engaged in a combined degree program, addresses the care ethic from a nursing background. Tricia Williams, a practicing dentist completing her comprehensive exams in the bioethics program, uses her clinical experience and theoretical understanding of patient autonomy to find expression in her piece.

The Center wishes to honor our contributors, encourage our students, and forward the work of Christian bioethics among our constituency.

Sincerely,

Mark F. Carr, PhD
Theological co-director
Center for Christian Bioethics

Paternalism and autonomy in dentistry

Tricia Williams, DDS

Today's students of ethics are generally indoctrinated to have an aversion to paternalism. Paternalism pervades many an ethical discussion as a pejorative term, describing the prominent doctor-knows-best model of patient interaction of decades ago. Some refer to these times as the "good old days," while others describe patient autonomy as the best thing since sliced bread. Medicine has undergone staggering changes in the last thirty years that many would not have predicted. Shifts in how health care is delivered have affected every aspect of medicine. Dentistry on the other hand, seems to have lagged a bit behind. It is my belief that dentistry, despite attempts to shift to the patient autonomy model, has retained an inherently paternalistic model of practice. Has dentistry, as a profession, thought enough about paternalism in everyday practice? And are the concepts of autonomy and paternalism adequately reflected in the professional codes and clinical practice of dentists? I will contend the answer to these questions is no; dentistry needs to begin a dialogue within the profession about the responsibility of dentists to recognize inherent paternalism in dentistry and foster autonomy in patient decision making. In the face of such changes, additionally, patient accountability must also be encouraged, as they participate in their dental care.

Historical beginnings

Historically, many trace the beginnings of paternalism to the Hippocratic Oath: "I will use treatment to help the sick according to my ability and judgment, but I will never use it to injure or wrong them" (Odom, 1991, p.12). Thus begins the Hippocratic tradition of doing what one thinks is in the best interest of the patient. This idea has gone on to be interpreted in many ways. The paternalistic model is rooted in the best interests of the patient, and the belief that doctors know best how to protect these interests.

In the United States, however, the emphasis on individuality and self-determination has led the way to the dominance of patient autonomy. A frontier spirit of individuality pervades much of American culture. This sentiment is certainly not localized to the United States, but also applies in other Western countries.

Case law and historical events have helped shape attitudes toward patient roles in health care. One of the earlier cases that expresses the need for patient autonomy is *Schloendorff v. New York Hospital (1914)*. A woman went into surgery for one procedure. While the patient was anesthetized the physician noticed a mole on the patient's face and removed it. The patient awoke from her anesthetic and was quite displeased that the mole had been removed. A lawsuit followed that challenged the ideas of paternalism that were pervasive at the time. Justice Cardozo in his opinion on the case stated "…Every human being of adult years and sound mind has a right to determine what shall be done with his own body; and a surgeon who performs an operation without his patient's consent commits an assault, for which he is liable in damages" (*Schloendorff v. New York Hospital [1914]*).

World War II brought about changes in higher education and technology, as well as a growing movement focused on civil and individual rights. The atrocities of human experimentation by the Nazi's precipitated a demand for proper respect of patient autonomy and informed consent. *The Nuremberg Code*, which sets forth ethical principles of human experimentation, spells out very specifically these demands: "The person involved should

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have legal capacity to give consent; should be so situated as to be able to exercise free power of choice, without intervention of any element of force, fraud, deceit, duress, over-reaching, or other ulterior form of constraint or coercion; and should have sufficient knowledge and comprehension of the elements of the subject matter involved as to enable him to make an understanding and enlightened decision." Post World War II professional codes required alteration to include the emphasis on patient autonomy. Despite the new found emphasis on patient autonomy, use of the term *informed consent* does not enter the mainstream of the health care lexicon until a decade later.

War further shaped attitudes toward self-determination and propagated an expression of disdain for authority in the Vietnam War era. Informed consent, as a term, only gains prominence following the introduction of the Patients Bill of Rights in the early 1970's. The emergence of managed care has further challenged the self-determination of patients and the authority of doctors. A transformation in the doctor/patient relationship has resulted. David C. Thomasma, PhD, points out that physicians and dentists, as a rule, are no longer primary decision makers in all aspects of health care (1983). Recent attitudes toward paternalism reflect the frustrations of any dynamic system. Paternalism survived centuries as an acceptable pattern of interaction. Then the changes in attitude precipitated by case law and war forced attention on individual rights, patient autonomy and informed consent.

> *"…paternalism often takes the form, not of overriding the expressed will of the patient, but of failing even to ask the will of the patient."*

Defining paternalism

It is important that we discuss the normative ethics of paternalism in health care. We must define paternalism and explore the implications of this in models of doctor/patient relationships. This task is not as simple as one might think, because there is not just one simple definition of paternalism. Definitions of paternalism are riddled with qualifiers and subtle variations that require explanation. Every author wants to add an adjective to paternalism; for example, "justifiable paternalism," "strong paternalism," "weak paternalism," "beneficent paternalism," and "rational non-interventional paternalism," to name a few.

Gerald Dworkin, in his 1976 book, takes paternalism to mean: "the interference with another's liberty of action justified by reasons referring exclusively to the welfare, good, happiness, needs, interests or values of the person being coerced." In some definitions of paternalism we merely see the principle of beneficence take priority over the principle of autonomy. This is the idea espoused by Albert R. Jonsen, PhD, et. al. in their definition of paternalism: "the practice of overriding or ignoring preferences of patients in order to benefit them or enhance their welfare" (Jonsen et. al., 1982). In other words, paternalism is not just coercing someone, it may simply be ignoring the person's expression of choice.

Dr. Thomasma (1983) states that paternalism does not respect the rights of adults to self-determination, and that autonomy does not respect the principle of beneficence. An example, a seventy-year-old woman is found to have pancreatic cancer. This woman has plans with her husband to take a trip to her childhood home in Germany. She states to the physician that she has plans and hopes he has no bad news. A strong paternalistic response might favor beneficent deception over truthtelling. Conjecture about potential detriment could eclipse the moral duty to tell the truth. The desired outcome would be to not ruin what could be the patient's final trip.

Paternalism, as defined by James F. Childress, PhD, (1982), is an action taken by one person in the best interests of another without their consent. He addresses two features of paternalism. The primary feature is the "altruistic beneficence," which aims to benefit another person. The second characteristic is a refusal to accept that person's wishes, choices, and actions in certain circumstances.

Paternalism may then be defined as a refusal to accept, acquiesce in, or even attend to another person's wishes, choices, and actions because they are not deemed to be in the best interests of that person.

As one can see there are varied explanations of what paternalism means. However, for our purposes I will define paternalism as: the actions taken by health-care professionals when they believe they know what is best for the patient, regardless of the expressed will of the patient. In the dental setting, paternalism often takes the form, not of overriding the expressed will of a patient, but of failing even to ask the will of the patient. If anything was learned from *Schloendorff v. New York Hospital* it is that health-care professionals must ask patients to express their will.

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Among the assorted definitions of paternalism, the dynamics of the doctor/patient relationship take on characteristics with subtle variations. It would be beneficial to explore briefly the models of doctor/patient relationships to illuminate the possible nuances these relationships provide.

Models of doctor/patient relationships

Attitudes of the doctor/patient relationship are framed by the implicit model in which the two interact. A review of the literature reveals dozens of models and many are redundant. All attempt to describe the relationship between doctor and patient, as well as between the doctor and his profession. The author who has set forth the most familiar models of doctor/patient relationships in dentistry is David T. Ozar, PhD, and I will limit our discussion to his models.

Dr. Ozar identifies four models as the most pertinent to ethical discussion in dentistry (1994): Guild Model, Agent Model, Commercial Model and Interactive Model.

The Guild Model focuses on the doctor's expertise and the patient's lack of it. The source of expertise is the profession, a community of doctors who preserve and advance knowledge. By definition, a guild is an organization of persons with related interests, goals, etc., especially formed for mutual aid or self-protection. A guild is organized to maintain standards and to protect the interests of its members; a guild sometimes constitutes a local governing body. It is because of the doctors' commitment to the profession that they undertake professional obligations. There are two morally problematic components to this model. Implicit in this model is the doctor's primary allegiance to the profession. Disharmony occurs when the doctor's first allegiance (the profession) comes in conflict with meeting the needs of the patient. Secondly, the patient is not viewed as an autonomous figure, because only the doctor has the expertise to judge patient needs. Ideals of respecting patient autonomy and acting in patients' best interests take second and third place to professional allegiance.

If decision making is entirely left to to the patient, it would be categorized as the Agent Model. In this model the doctor only acts as an "agent" for the patient. Although this model has an autonomous role for the patient to play it does not create a favorable role for the doctor. The doctor's knowledge is all that is required from the patient. There is no desire in this model for a caring interactive relationship, the doctor must only respond to the wishes of the patient. One could liken the role of the doctor in this model to that of a waiter. The patient places his order and the doctor does his bidding. The Agent Model is not likely to serve as a useful scenario in the world of health care. It places the "ethical commitments" of a health-care professional at risk. Professional commitment to the welfare of the patient does not guide this relationship.

The doctor in the Commercial Model is reduced to merely a producer of goods. The ethics of commercialism do not bind the doctor to any high moral standard. The concept of professional is lost in this model. The doctor is not bound by his commitment to the profession or to the patients to act in their best interest. In this model the patient is reduced to the status of a customer or client. The goal of the doctor is to sell or service. A doctor/patient relationship based on this model seeks rewards of a financial kind. The patient (consumer) wants a good product at a low price. The doctor wants to provide that product and gain a profit. This model does not focus on patient needs, commitment or whole-person care.

Assumption of the Interactive Model considers the patient to be a decision maker, but also as a sick person in need of care. There are three important aspects of equality in this model. One, doctor and patient have equal standing as decision makers and both deserve respect. Two, each is trying to live by a set of values. Three, decisions about the patient's health are facilitated by communication and mutual cooperation. In the Interactive Model the sick patient seeks out the expertise the doctor possesses in hopes of restoring health. As such, autonomy is respected. The doctor respects the body of the patient, seeking to aid in the return of control and health to the patient. The Interactive Model favors collaboration. This collaboration commits the doctor to working to enhance the patient's autonomy.

These models give us a sense of the range in doctor/patient relationships. However, these are theoretical constructs and no dentist or patient fits exactly into any one model. It is important for dentists to locate themselves in this range of models, and realize doctor/patient interaction will differ greatly from case to case. A number of variables influence the spectrum of doctor/patient relationships. Variables such as age, culture, gender, and education often effect how treatment decisions are presented and made.

Building on Dr. Ozar's insights, I propose a model that could be normative for dentistry. From the perspective of one who practices clinical dentistry, I contend that a model should have some of the following characteristics. The dentist should acknowledge the patient as a potential decision maker, but realize that not all patients will attempt to participate in decisions. We should recognize that equality of power does not naturally exist in the doctor/patient relationships, largely due to the variables mentioned above. It is important to foster communication and mutual cooperation in decisions about the patient's health, however this cannot occur unless there is an effort made by both parties. The patient's effort should include desire and ability to attain, comprehend, and process pertinent treatment information. Doctors must ask, inform, and listen to patients and not accept silence as a tacit consent. True collaboration between doctor and patient requires active participation from both. Interaction is not enough. Doctors must seek to ascertain the expressed will of the patient. I will call this model the Active Participation Model of Doctor/Patient Relationships. The Active Participation Model will have challenges and implications in clinical practice. However, it is an ideal for which we must strive as a profession.

Dental practice realities

American society is inundated with information about medicine. There are newspaper and magazine articles, web sites, special segments on the nightly news, and one hour dramas like *ER* and *Chicago Hope*. Patients are exposed to medical terminology and information in ways unlike 50 or even 30 years ago. This increase in the patient's medical information "IQ" has helped to foster the focus on autonomy and self-determination. Patients expect information from their physician, and many expect the physician to involve them in decision making. In my experience, dental patients do not attempt this same level of active interaction. There is no television drama that chronicles the experiences of dentists in action. Many patients do not know, or care to know, the particulars of their dental treatment. The explanation for this is simple: for the patient, medical decision making is different from dental decision making. In medical decision making, the patient often has to decide whether to have a particular procedure done or not. The medical decision often does not involve a selection of procedures to do. Moreover, medical decisions often feel compelling because of the gravity of what is at stake, including, at times, life itself.

In contrast, in dentistry, there are seldom life and death issues. So dental decisions often become more like buying a new car or other commodities. What options and features should the patient choose? How much can he or she afford? And how can the treatment be financed? Simplified further, often the primary concerns of dental patients could be broken down into these two questions. First, how much is this going to hurt? Second, how much is this going to cost? Other information is often viewed as superfluous technical jargon, not pertinent to decision making.

Mae, a 63-year-old grandmother, waitress and 50 pack-a-year smoker, was treated in my practice. She is a good illustration of patient indifference to active decision making. She presented with poor oral health, a case of neglect. I carefully documented the clinical findings of periodontal disease and caries. We discussed the negative effects of years of smoking and neglect on her dental health and how we might arrest the disease process. Mae listened intently as I described oral pathogens, materials, techniques, treatment benefits, and contraindications. Her response at the end of my discourse on dental treatment materials and modalities was not to participate actively and engage me with questions. Her reply was simply, "Whatever you think is best dear. I know you'll choose what's best for me." I would like to say this was an isolated event, but I cannot. Many dental patients do not actively participate in attempts to educate and inform.

Disclosure of information to dental patients is not a simple task. David Nash states in his *Journal of the American Dental Association* article, that the dentist is obligated to disclose all the information a rational person would desire to know in arriving at a decision, but must do so in a manner that ensures patient comprehension (1984). This is accomplished by processing the information in a reciprocal manner—asking for a patient validation of understanding and requesting and responding to questions. The information desired by a rational person can be correlated with how important the person believes a decision is. If making a decision is related to a medical problem of life and death proportion, then often times more information is desired. That, however, does not mean an expression of autonomy is necessarily more important if life is at stake. Respect for a person's expression of will extends to large and small matters in life.

In the simplest of terms, I observe two kinds of dental patients who seek care. First, there are patients who are concerned about their teeth and want to maintain dental health. Second, there are patients concerned about their teeth only when they hurt. The first group contains within it patients desiring different amounts of information. However, there is a baseline of information needed to accommodate this group. The second group often requires the most treatment, but also (with rare exception), desires the least information. These patients are often more likely to let cost dictate their dental treatment. The situation is obviously disproportionate and a source of frustration to the dentist seeking to adequately inform the patient. Literature often instructs that the dentist can gain the patient's consent only after the opportunity to freely and intelligently consider the options (Nash, 1984). This type of communication is a challenge in dentistry, and what should exist as the standard of informed consent. Such a standard of informed consent is imperative if we are to implement the Active Participation Model.

The care of Mr. Casson illustrates this challenge. He was a 75-year-old patient in need of a great deal of dental work. He was missing multiple posterior teeth and needed restoration of function. A comprehensive treatment plan was constructed with multiple treatment options and presented to him.

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Attempts to inform him in common language about the indications, risk and benefits, mechanics, and cost of his options were admirably carried out by the dentist. The patient did not respond in a "reciprocal manner" (Nash, 1984) and obviously lacked a desire to comprehend his treatment plan. He was not incompetent. He was just not interested. This scenario plays itself out in varied forms in dental offices, everywhere, everyday.

The paternalistic model of patient interaction in dentistry is often expected by a patient. Pellegrino argues that, when properly used in a caring effort to enhance individual autonomy by educating patients, the paternalistic model is praiseworthy and responsible (1988). Is it possible that much of decision making in dentistry is justifiable paternalism? If so, patients may be more inclined to let someone else decide what to do, particularly if they trust their caregivers to do what is best. However, this attitude is not ideal. We should ask patients to express their will. Our goal should be to obtain truly informed consent. To obtain the ideals of the Active Participation Model we must see change both in doctors and in patients. Paternalistic practice is often perpetuated by the apathy and complacency of patients regarding the particulars of the dental care, but individual dentists and organized dentistry must precipitate change. If we fail to do this it is likely the legal system will do it for us.

Recent events reflect the need for change in dentistry. A complaint was filed in Los Angeles against the American Dental Association (ADA) and California Dental Association by an organization called Kids Against Pollution. This suit claims that amalgam is harmful and that mercury should no longer be used in dentistry. The complaint rehashes arguments about dental materials that are not new to dentistry. However, the existence of such a suit is fundamentally troubling and pertinent to our discussion. Patients must be informed and consent to treatment acquired. This consent includes what kind of materials are placed in a patient's mouth. The ADA's response to this suit in a news release states "the ADA has long held the view that dentists should not induce patients to accept dental treatment by using misleading information or information not based on the best scientific evidence. That's what the ADA's ethics rule is all about—protecting patients" (ADA News Release, June 2001).

The ADA Principles of Ethics and Code of Professional Conduct address the principle of patient autonomy. Section I states, "The dentist has a duty to respect the patient's right to self-determination and confidentiality." This principle is further discussed, as the ADA states: "Under this principle, the dentist's primary obligations include involving patients in treatment in a meaningful way, with due consideration being given to the patient's needs, desires and abilities, and safeguarding the patient's privacy." Section 1.A. directly addresses patient involvement. "The dentist should inform the patient of the proposed treatment, and any reasonable alternatives, in a manner that allows the patient to become involved in treatment decisions." The language in the professional code is crafted to retain some semblance of paternalism. In the absence of interpretive statements or case law the principles are vague. Phrases such as "to become involved" sound like an invitation for a patient to join in. Not exactly words that speak of active participation. The idea of presenting any reasonable alternatives is subject to some confusion as well. What is considered reasonable by one dentist may not be so for another.

There is a great spectrum of reasonable alternatives influenced by many factors, not the least of which is financial. A good example would be the treatment options available for a patient with a missing tooth. The spectrum would include a removable appliance, fixed bridge or dental implant. However, sometimes paternalistic attitudes influence the situation and a patient may only be offered the first two treatment options. Yet, as implants increasingly become the standard of care, dentists could be held legally responsible for not adequately informing a patient. The ADA should address these ambiguities in the professional code and strive to place a greater emphasis on informed consent and furthering patient autonomy.

Practice ideals

There is no question that doctors should aspire to practice their profession morally. However, questions do arise about how to accomplish moral practice. The ethics of the profession derive from the role assumed by the doctor in agreeing to enter into a relationship with another human to "do good" for the individual with regard to health (Nash, 1984). William F. May, PhD, seeks to encapsulate the relationship entered into by professional and patient by describing this relationship as a covenant. This covenantal relationship is entered into by doctor and patient. However, the covenant goes beyond the doctor/patient relationship and extends to include the profession and society (1983). A covenantal relationship implies that the duties of the doctor apply beyond the patients they directly interact with and extend to the whole of society.

An obligation of this kind could be a bit overwhelming. It is worthwhile to explore why the profession has a covenant with society. Society provides the bequest of education and self-government in return for the professional's inherent talents and abilities. Society promises the health professional that it will grant self-governance and opportunity for personal gain. The profession, in turn, promises to serve society fairly and faithfully. Consequently, professionals become doctors and individuals of society patients. "The health professional is transformed from ordinary citizen to healer" (Nash, 1984). Each time a doctor and patient establish a relationship this covenant is reconfirmed.

Once the relationship is established the doctor begins to pursue the goal of the relationship, beneficence, doing good. Benefiting the patient is accomplished by providing the best care possible. It is necessary to take into account the clinical circumstances: patient understanding, the profession's current understanding, and the patient's desires. It is critical to recognize patient vulnerability. There is an imbalance due to the technical training of a doctor that must be balanced by conveying sufficient information to the patient. Because of the doctor's expertise he or she must take initiative in controlling the imbalance of the relationship. The attempt to inform or educate the patient is demonstrated in Dr. Ozar's Interactive Model and in my proposal for an Active Participation Model. In order to precipitate change and aspire to the Active Participation Model we must lobby for a change in our colleagues, the attitudes of our patients and in organized dentistry. Our ultimate goal in doctor/patient relationships should be to treat disease while upholding the principles of patient autonomy and informed consent.

Practice solutions and conclusions

Many dentists find the indifference of patients to treatment decisions as repugnant as many ethicists find paternalism. The question is: What can be done to change the existing pervasiveness of paternalism in dental practice? There is little open opposition to the conversion of dentistry to autonomy models. Dentists are motivated to embrace a practice philosophy that would encourage patient participation and self-determination. There are altruistic motivations as well as numerous benefits to the dentist. Patients who understand what their dental treatment entails are far more likely to appreciate their dentist's skills. It is important when a dentist leaves the office in the evening that he or she feels good about what has been accomplished. The value of patient appreciation for dental skills is inherent to the autonomy model. The value of a well-informed and educated patient is significant. Patients who comprehend treatment options will value quality and seek more comprehensive treatment. This will result in benefit to the patient as well as the dentist.

Dentistry sits on a great precipice, positioned for change. The historical progress of thought through world events and changes in public policy have helped precipitate new models of doctor/patient relationships. Emphasis has gradually shifted from paternalistic attitudes of doctors toward patient self-determination and autonomy. This shift has served as a watershed for dialogue and codification of appropriate models of doctor/patient relationships. However, more must be done. Organized dentistry should strive to make stronger and clearer statements in the Code of Professional Conduct about informed consent and patient autonomy. Dentists and patients should seek active participation in treatment planning. In clinical practice, we, as dentists, should never be guilty of not asking a patient their express will in dental treatment.

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Care ethics in pediatric critical care nursing

Georgina Manning, BSN

In the search for new ways of providing care and meeting the needs of patients, medicine and technology have surpassed their original intentions. Technological advances are now keeping children alive while their quality of life and severity of their disabilities are turning into an existence consumed by suffering.[10] As a result, nurses are confronted more and more with ethical dilemmas. Some of these ethical dilemmas include life and death issues regarding uncertainty, the initiation and/or removal of life support, selection or exclusion as a potential recipient of an organ transplant or administering an experimental drug to a child who is too young to give informed consent.[6]

Chris Gastmans, PhD, Bernadette Dierckx de Casterle, PhD, and Paul Schotmans, PhD[9], describe the moral practice of nursing as providing good care. Drs. Gastmans, Dierckx de Casterle, and Schotmans contend that care can be considered a foundational normative concept in the ethics of the nursing profession.

Ethics & nursing

Tom L. Beauchamp, PhD, and James F. Childress, PhD, describe ethics as a "generic term for various ways of understanding and examining the moral life."[2] There are, at least, two approaches to ethics, normative and nonnormative. Normative ethics is described as a "form of inquiry that attempts to answer the question 'which general moral norms of the guidance and evaluation of conduct should we accept and why?'"[2]—that is, to identify the general moral norms of nursing practice used to guide and evaluate the conduct of nursing and their relation to care ethics.

The tradition of nursing is traced back to the Victorian era during Florence Nightingale's revival of altruistic nursing and the covenant of care. The covenant of care, as stated by Ann Bradshaw, "arose from Judaeo-Christian imperative of care for the stranger, agape, as exemplified in the story of the Good Samaritan."[4] Traditionally, the purpose of nursing was caring for the sick. Although health care has changed over the last one hundred years, the moral tradition of altruisim remains fundamental to the nursing profession.

Nursing, as a moral practice, is based on the obligation of promoting the well-being of patients by means of a caring relationship.[5] Drs. Gastmans, Dierckx de Casterle, and Schotmans describe nursing practice as the "totality of skills and attitudes (caring behavior) that are applied in the context of a particular caring relationship, with the intention of providing good care (the goal) to the (usually sick) fellow person."[9] Nursing, as a moral practice, consists of three main components: the caring relationship, caring behavior and good care. The caring relationship consists of the relationship between the nurse and patient. Caring behavior involves the integration of virtue and expert activity of nursing practice. The goal of nursing is to promote the well-being of the patient by providing good care on all levels, including physical, psychological, relational, social, moral and spiritual.[9]

Caring, caring relationships and caring behaviors

Caring is defined as a "behavior or set of behaviors that stem from a strong opinion, feeling, concern, or interest in something or someone that contributes to the good worth, dignity or comfort of someone."[8] In nursing, the caring relationship is a professional one that originates from a situation where one individual is in need of caring, as a result from an illness, crisis or the inability to care for himself or herself.[7] From this perspective, the caring relationship is "a way of relating oneself to the other in relational context with focus on development and maintenance of the other and oneself."[9] In nursing, the caring relationship not only includes the patient, but the entire family. Parents, siblings, and grandparents are also in need of caring during times of illness or crisis. Therefore, in pediatric nursing, caring not only relates to the child, but to the family in a relational context, focusing on the development and maintenance of the child, family and nurse.

Caring is carried out through behaviors that involve the integration of virtue and expert activity of nursing practice.[9] The virtue of care can help nurses reach the goal of good care. The virtue of care is described as having two dimensions, cognitive and affective. The cognitive dimension involves knowledge of the situation of the person in need, while the affective-motivational involves being emotionally touched and motivated by what happens to the patient.[9] The virtue of care is concerned with the factual, concrete condition of the individual. From the cognitive dimension, the pediatric nurse should be knowledgeable of the situation of the person in need. For example, a nurse caring for a child who was involved in an automobile accident would need to be knowledgeable about the injury to the child, the age and developmental stage of the child, medical history, whereabouts of parents and family members, and others involved in the accident. The affective-motivational dimension includes the response to the event (a child in need of care) resulting in a motivation to provide good nursing care to the patient and family. Hence, the cognitive and affective dimensions of the virtue of care are not separate components, rather they inform one another.[9]

The expert activity of nursing that relates to caring behaviors can best be described by the work of Patricia Benner, PhD, RN, *From Novice to Expert.*[3] In her work, Dr. Benner identified seven domains and competencies of nursing practice. In nursing practice, the domains of the Helping Role and Teaching-Coaching Function specifically focus on the nurse-patient relationship.

The Helping Role focuses on establishing a relationship with the patient and establishing a commitment to healing. The competencies in this domain focus on comfort, support, communication, and preservation of personhood. In pediatric critical care nursing this would include establishing a relationship with the patient and family in order to provide comfort, support, and to foster communication between the nurse, patient, and family. By doing so, the pediatric critical care nurse is able to guide the patient and family through recovery and emotional and developmental changes. The teaching-coaching function focuses on the patient and his/her illness. In this domain, competencies include the understanding and integrating of illness and recovery into the patients and family lifestyle.

The competencies and behaviors identified by Dr. Benner are similar to the caring behaviors identified by Sara T. Fry, PhD, RN; Aileen R. Killen, PhD, RN; and Ellen M. Robinson, PhD, RN.[8] In the article, Drs. Fry, Killen, and Robinson discuss aspects of caring nurse behaviors based on responses from patients, nurses and the general public. Results were obtained through the analysis and synthesis of nine research studies on caring. Based on their findings, Dr. Robinson conducted a new analysis of nine other studies and identified twenty-six aspects of caring nursing behaviors.

When combined, the authors presented a preliminary list of eleven identified aspects of caring behaviors. These include empathic communication, presence, competence, trusting relationship, meeting patient needs, respect, providing continuity of care, advocating and being nonjudgmental and solicitous. Although the list is preliminary, interestingly, the domains and competencies identified are similar to those noted by Dr. Benner. Therefore one can conclude that the expert activity of nursing and the virtue of care can best be demonstrated though caring behaviors.

The third component of the moral practice of nursing is good care. The goal of good care is promoting the well-being of the patient on all levels—physical, relational, social, psychological, moral, and spiritual. Good care in the physical aspect includes maintaining and improving the patient's physical condition. Not only does this include maintenance and promotion of the body, as in feeding and bathing, but the respect for the human body, privacy and dignity.[8] Respect, privacy and dignity for the human body requires that the nurse respect the physical condition of the patient at all times. In pediatric nursing, it is important for the nurse to respect the human body, even in the midst of medical emergencies, treatments, and procedures, which require a child's body to be exposed.

The relational aspect focuses on promoting the development of "more profound human contact."[8] Dr. Gastmans, et. al., states that good care must promote the person in his or her relational dimension. This includes planning and promoting human contact. In pediatric nursing, this includes allowing families to remain at the bedside with their child and/or scheduling visiting times for families and friends. Involving the family in the care of the child not only promotes human contact, but encourages the relationship between parent and child. The pediatric nurse, through touching such as in rocking or holding the child, can also promote human contact.

The social dimension involves social institutions, organizations and societies that relate to the patient.[8] Dr. Gastmans, et. al. describes the health-care system as an example of a social institution. In the health-care system, the nurse functions as an advocate for the patient and their family. This involves protecting or affirming the rights of the patient within the health-care system or the hospital setting.

In pediatrics, many patients are not able to exercise their power of self-determination; therefore the nurse may assume the role of advocate. Advocacy in pediatric nursing may require the nurse to speak on behalf of the patient. As an advocate, this includes respecting the autonomy and integrity of the patient and family, and protecting the child from harm.[6] Dr. Gastmans, et. al. states that the nurse must also focus her attention to and advocate for those in greatest need and whose access to health care is difficult.

The psychological dimension calls for the nurse to protect the uniqueness and originality of every patient.[9] This is demonstrated by respecting the individuals for who they are. The nurse can only advocate for the patient if the nurse understands what the meaning of life is or could be for the patient. In pediatric nursing, this involves understanding what is important for the patient, as well as, his or her family. Respect for the patient and family's culture, values, beliefs, and assisting the patient and family in fulfilling their moral obligations.

The moral dimension involves appreciating the patient as a moral subject and focuses on the patients' self-determination. This involves respecting the autonomy of the patient, allow-

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ing the patient to make his or her own decisions, the right to be informed of choices and to be free from coercion. Pediatric patients will lack life experiences and knowledge to exercise their own decision-making. Therefore the nurse must provide the opportunity and necessary information for families to make decisions about their child.[6]

In regards to the spiritual dimension, good care requires the nurse to respect the patients' spiritual needs and to assist in his or her fulfillment.

In summary, caring relationships, caring behaviors and good care hold a common theme—respect and caring for the patient. Therefore, in the moral practice of nursing, respect and caring are the generally accepted moral norms guiding and evaluating the conduct of nursing practice. Bridghid Kelly[11] presents the concepts of respect, caring and nursing, and their relationship in the following eight propositions:

> The practice of nursing is essentially moral in nature. Respect for persons and caring are ethics in nursing. Respect as a nursing ethic, is evidenced by respect for clients and families, self, colleagues, and the profession.
>
> Caring as a nursing ethic, is evidenced by caring for clients and families, self, colleagues, and the profession. Respect and caring are necessary but not sufficient elements in nursing. Respect precedes caring in the nurse client relationship. In the absence of respect, caring cannot take place. In the absence of caring, nursing does not take place (p. 73).

"…respect and caring are generally accepted moral norms guiding and evaluating the conduct of nursing practice."

Respect for the person is necessary for the caring relationship to take place and both the nurse and patient must see and treat each other as equals. In pediatric nursing, although the nurse and patient may not view themselves as equals, as in the case of an infant or critically ill child, the nurse and family must see and treat each other as equals. Having identified the moral norms of nursing practice, I will now discuss care ethics as an ethical foundation in pediatric critical care nursing.

Care ethics in pediatric critical care nursing

"Ethical decision making is central to every nursing act. Decision-making grounded in ethics is not a particular mode of reasoning to which one refers in certain situations. It is an element of nursing."[11]

"Ethical behavior is not the display of one's moral rectitude in times of crisis. It is the day by day expression of one's commitment to other persons and the ways in which human beings relate to one another in their daily interactions."[11]

An ethics of care values the personal relationships of the individuals involved. The moral responsibility and possible choices are defined by the context of the relationship. The process involves identifying the problem within its context, considering others involved, and how they are interrelated, feeling concern for individuals and relationships through sympathy, compassion or friendship, and identifying oneself in relation to the individuals and problems involved.[8] Drs. Gastmans, Dierckx de Casterle, and Schotmans[9] state that the ethical task of nursing consists of fostering the caring relationship to progress as much as possible toward the moral good understood as good care. Having established respect and care as moral norms of nursing practice, and the definition of care ethics, I propose care ethics as an ethical foundation for pediatric critical care nursing.

Opponents of care ethics as an ethical theory argue that care ethics is incomplete, lacks comprehensiveness, explanatory and justificatory power, is oppressive to women, requires one to act partially, and rejects traditional moral principles of justice and impartiality.[2] It is through a reflective narrative of personal experience that I will bring to light the full capacity of care ethics in resolving ethical dilemmas, such as ones of removal of life support, and the day-by-day expression of nursing's commitment to other persons.

Joel was a 2-year-old boy who was diagnosed with Non-Hodgkin's Lymphoma at 18 months of age. As a staff nurse for a pediatric unit, I was Joel's primary nurse. Over the course of eight months, I took care of Joel and his family. I grew to know Joel's mother, father, grandparents, aunts and uncles. Joel was in the hospital for weeks at a time, sometimes not being able to go outside or run around like most toddlers do at this age. During the late hours of the night, Joel and I would have water gun fights with syringes, practice counting, saying the alphabet, and playing baseball with a hand towel rolled up and our hands as bats. My relationship with Joel and his family was one that flourished out of the respect for Joel and his family. Joel's parents were very loving and supportive, and wanted everything done for him, for he was their only child. After six months of treatment, it was evident that Joel was not responding to treatment and that his condition was worsening. Joel's physician wanted to try more aggressive treatment and did not want to give up. As I transferred to work on the pediatric intensive care unit, so did Joel. At this point he was intubated, receiving continuos blood transfusions, dialysis, and cardiac support drugs. It was 1:15 p.m. when Joel's heart stopped beating and cardiopulmonary resuscitation was initiated. While the doctor was yelling out orders, I was pushing blood and other fluids in hope of maintaining a blood pressure. During this time the parents were asked to step outside. After thirty minutes of coding Joel, it was evident that Joel would not be revived. As an advocate for Joel, and out of respect for him and his family, I asked the physician to terminate the code. At 1:55 p.m. the code was terminated and at 2:00 p.m. Joel died. Looking back, I ask myself what made me ask for termination of the code? Respect and caring.

Nursing, as a moral practice, is based on the moral obligation of promoting the well-being of the patient by means of a caring relationship. Caring relationships are maintained through respect and caring. The only way I could promote the well-being of Joel and his family was by terminating the procedures and medications that were prolonging his life as well as the suffering that came along with it. Continuing life support and prolonging his life would not promote the well-being of Joel and his family, rather, it would go against my moral obligation.

It was through respect for the human body and dignity that I asked for his body to be left alone. And it was the same respect that provided the strength to clean his body before his mother and father could come in and see him. It was through the holding of his hand and his mother's while he was dying, that promoted the human contact. It was empathy that allowed me to cry alongside his mother, as she held him one last time. Having knowledge of his situation, understanding what life meant to Joel and his family and respecting his family's culture, values, and beliefs, allowed me to act as an advocate. As an advocate, I was able to protect him from further harm.

By identifying the problem within its context (terminally ill child), considering others involved (parents, grandparents, aunts, and uncles) and how they interrelate, and feeling concern for Joel and his family through sympathy and compassion, I was able to identify myself in relation to Joel, his family, and his illness. It was through care ethics that I was able to fulfill my moral obligation in promoting the well-being of Joel and his family. In this case, Joel and his family's well-being involved allowing him to die. The care and respect between the nurse, patient, and family is subjective and varies with each individual, and therefore cannot be limited by rules or principles. If critics of the care ethic are correct, perhaps this is where care ethics lacks completeness, comprehensiveness, and impartiality in that it fails to capture the full dynamics of such complex and intimate relationships.

In conclusion, nursing as a moral practice is based on the moral obligation of promoting the well-being of patients by means of a caring relationship. The caring relationship provides a foundation for ethical decision making and a place for care ethics in pediatric critical care nursing.

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