



Bioethics: a patient advocate role for Osteopathic Family Physicians

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KEYWORDS:

Bioethics; Family physician **Summary** The underlying holistic principle and philosophy of osteopathic medicine provides a strategic advantage for osteopathic physician participation in bioethical decision making for the benefit of patients; the broad-based education, training, and experience of the osteopathic family physician provides additional insight not readily available from other physicians. As the conceptual framework of the patient-centered medical home model advances as a desired care delivery model, as the increased use of hospitalists continues for inpatient management supplemented by single-discipline specialists and subspecialists, as discontinuity grows due to care rendered by multiple specialists as patients experience the intricacy of chronic condition interactions resulting from medical advances that prolong the human lifespan, and as more patients have advanced medical technology applied to their care, the osteopathic family physician's contribution to assist patients in managing this complexity will significantly increase in value.

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Ethics is a code of values which guide our choices and actions and determine the purpose and course of our lives.

— Ayn Rand, Russian-American novelist and philosopher (1905-1982)

What do we mean by bioethics?

The modern conceptual construct for bioethics emerged during the mid-20th century. It differed radically from the previous iterative domain of medical ethics that was characterized by a focus on professional codes of conduct. Biologist and eco-scientist Van Rensselaer Potter² first suggested the term *bioethics* to describe issues associated to improved human survival and quality of life. Over time, bioethics has expanded to include moral problems related to the life sciences, intrinsically medicine and biology; how-

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ever, the impact also includes environmental, social, legal, and political events including associated health policy.

A brief history of bioethics: fundamental to profound understanding

Exploring the evolution of bioethics reveals it developed in response to three critical stimuli: human rights violations in medical research, societal mores changes, and emergent biomedical technologies.

• The response to gross violations of human rights in medical research has multiple examples from the early to middle of the 20th century such as the eugenics and racial hygiene movement, the subsequent medical experiments in concentration camps during World War II, and the Tuskegee syphilis study (Figure 1).³

In each of these examples, subjugated individuals were coerced to participate absent their ability to consent or refuse participation. The United States Congress studied

The New York Times

Syphilis Victims in U.S. Study Went Untreated for 40 Years

By JEAN HELLER

WASHINGTON, July 25—For 40 years the United States Public Health Service has conducted a study in which human beings with syphilis, who were induced to serve as guinea pigs, have gone without medical treatment for the disease and a few have died of its late effects, even though an effective therapy was eventually discovered.

The study was conducted to determine from autopsies what the disease does to the human body.

Officials of the health service who initiated the experiment have long since retired. Current officials, who say they have serious doubts about the morality of the study, also say that it is too late to treat the syphilis in any surviving participants.

Doctors in the service say they are now rendering whatever other medical services they can give to the survivors while the study of the disease's effects continues.

Dr. Merlin K. DuVal, Assistant Secretary of Health, Education and Welfare for Health and Scientific Affairs, expressed shock on learning of the study. He said that he was making an immediate investigation.

The experiment, called the Tuskegee Study, began in 1932 with about 600 black men,

Figure 1 The New York Times seminal exposé.

the occurrence of such rights violations; it deemed that protections should be codified, resulting in the National Research Act of 1974 creating oversight of medical research to ensure human rights protections. The Act created the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. The Commission issued the *Belmont Report*⁴ describing ethical research principles. Adherence to the principles expressed in the *Belmont Report* remains a requirement for all federally approved institutional research boards (committees) providing oversight for all human research in the United States: respect for personal autonomy, beneficence, and justice.

 The response to major social transformations exemplified by the human, civil, and patients' rights movements in the United States changed not only the legal but the interpersonal relationship between patient and physician. In the bioethical realm, this affects the concepts of patient autonomy and the framework of informed consent.

The general legal right to self-determination (and by extension the right to be adequately informed of options) in the United States was succinctly codified by Justice Cardozo in a 1914 New York court case: "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." The paternalistic construct and perceived duty of physicians to withhold information

that contained poor prognoses from patients was co-extant at the origin of the era of these social transformations. In an article in 1961 Oken noted that 90% of physicians reported they did not inform patients of a cancer diagnosis. The results of these social rights movements have altered that relationship.

• The response to new biomedical technologies and scientific discoveries, exemplified by mechanical ventilators and reproductive advances such as in vitro fertilization, organ and tissue transplantation, the genome therapies, and recombinant DNA research, ushered in a wide range of new bioethical issues. Dominant among these issues was the requirement for a new definition of death in view of of the introduction of sophisticated interventions using artificial life-prolonging support technologies.

An early notable case involved a young woman, Karen Ann Quinlan, who, after being placed on mechanical ventilation, was subsequently deemed to be in a persistent vegetative state. When her physicians opined that she would never recover, her parents requested discontinuation of the ventilator. Quinlan's physician argued that in the absence of brain death, medical and ethical standards required continued treatment—including use of the ventilator. Concomitantly, the State of New Jersey intervened with the legal presumption that the state's interest in protecting the sanctity of life must be protected and that discontinuing mechanical ventilation was tantamount to criminal homicide. At trial, the New Jersey Supreme Court ruled that the parents could act in their daughter's interest and have the ventilator removed. As a result of this decision, alterations have occurred ranging from influencing physician-patient interaction to affecting public discourse on the provision of health care.

The bioethical issues resulting from technologic expansion often arise as a result of unintended consequences that cannot be foreseen before applying the technology to individual patients; confounding the benefit equations are health care economics and regulations that fail to keep pace with these advances.

General bioethical principles

Following the framework described in the *Belmont Report*, Beauchamp and Childress expanded the concepts by proposing four principles to support the foundation and the deliberations related to bioethical decisions and actions: respect for autonomy, beneficence, nonmalfeasance, and justice.⁸

The principle of respect for autonomy encompasses respect for individual decision making. This principle includes the elements of informed consent, confidentiality, absence of deceit (or withholding of crucial information), the right of patient refusal, and advanced care planning. To achieve this respect requires effective communication between physicians and their patients.

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Table 1 Examples of bioethics consultative facilitation issues

Abortion

Advance care planning (e.g., advance directives)

Confidentiality of medical records

Contraception

Conflict of interest

Consent or refusal of medical therapies

Donated organ or tissue use

Genetic testing

Inappropriate requests by patients

Informed consent

Medical futility

Pain management

Reproductive rights

Suicide, assisted suicide, and euthanasia

Surrogate mothers

Use or withholding of artificial hydration or nutrition

When to use withhold life support

- 2. The principle of nonmalfeasance encompasses the medical adage of "do no harm," an oft-quoted concept derived from the *Hippocratic Oath*: "And I will use regimens for the benefit of the ill in accordance with all my ability and my judgment, but from [what is] to their harm or injustice I will keep [them]."¹⁰
- 3. The principle of beneficence connotes doing good for individuals and in medical terms frequently refers to the obligation to promote health. However, whenever physicians attempt to assist others, they also risk harming them. This dichotomy requires that physicians simultaneously consider this principle with the nonmalfeasance principle because of potential misalignment of the two. What may provide personal benefit to one patient may be at odds with that of a similar patient with comparable options—for example, an acceptable life-saving medical therapy for one patient may conflict with the religious tenets of another. Growing emphasis on cultural competence and diversity accommodation has added new constructs to this principle.
- 4. The principle of justice connotes treating all individuals fairly, with reasonable distribution of burdens, benefits, or risks. Conceptually this occurs more in issues of health policy and population medicine rather than individual situations involving the distribution of limited medical resources, although these may occur in everyday clinical practice when insufficient resources exist to meet the needs of all patients (e.g., rationing of blood for transfusion during acute shortages).

Context for consultative participation in bioethical decision making

Physicians participating in bioethical decision-making situations, whether in the context of a bioethics committee Clinical problem → history → physical exam → ancillary testing → differential diagnosis/assessment → supplemental diagnostic evaluations as needed → treatment plan

Figure 2 Clinical reasoning.

"Clinical" ethical problem → medical facts → physician goals → patient goals → contextual or value-based considerations → ethical assessment → additional information and discussions (if needed) → recommended action

Figure 3 Clinical ethical reasoning.

assignment or in everyday clinical practice, should render their opinion by way of a values-based consultative process guided by the aforementioned principles. A values-based participant must understand cultural differences and perspectives to be just, fair, and beneficial in bioethics facilitations. Table 1 provides examples of clinical bioethical issues that a physician might encounter.

The heuristic is based on:

- Values that represent essential elements that guide action or reflect preferences held by individuals in a community. A natural tendency exists to imagine values as relatively static intrinsic principles, standards, virtues, and social norms possessed by individuals, groups, and societies that serve as inputs to and outputs from decision-making processes. Within the context of bioethical decision making, a dynamic aspect exists with a personal assignment of consequence or by establishing or modifying evaluations.
- Value judgments that may result in praise or blame; they
 may cite virtues or vices. A dynamic process culminates
 from the sorting out, stratification, and prioritization of
 the praiseworthy versus blameworthy to guide decisions
 and actions.
- Morals that comprise the set of values held by an individual and maintained by the individual's principled community. Morals define what constitutes a good life.
- **Morality** defines the system of values inclusive of moral rules, goals, and virtues that derive from those values.
- Beliefs, stemming etymologically from the Old English meaning "that which is beloved," which represent that which is valued highly by an individual. Beliefs guide an individual's interpretation of reality and, hence, the analysis of selected life situations.
- Ethics, which represent the culmination of the systematic examination of the values held by individuals in community.

Application of the heuristic to clinical ethical reasoning

Kaldjian et al. posited that clinical reasoning and clinical ethical reasoning, while sharing some commonalities, differ in tone and content.¹¹ Comparative logistics include the sequences shown in Figures 2 and 3.

Osteopathic Family Physicians participating in valuesbased bioethics facilitations have the potential to contribute

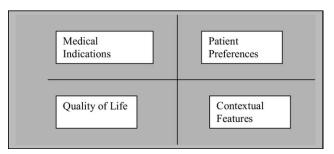


Figure 4 The Four Boxes: how to analyze an ethics case.

substantively to these deliberations, particularly when they have had an ongoing clinical relationship with the patient. Their intricate understanding of the impact of multisystem chronic conditions coupled with knowledge of interpersonal relationships within the family or supportive caregivers provide insights frequently unavailable to other physicians involved in the patient's care. Physicians seeking to participate in these bioethical facilitations should attain comprehensive understanding of an effective, systematic approach such as that outlined in Figure 4.

Jonsen et al. described one systematic approach for participation in bioethics case facilitation by using the Four Boxes¹² approach (Figure 4).

The initial phase of the process requires that the physician describe the problem clearly to confirm that a bioethical issue exists. This includes a statement of the medical problem(s) comprising the medical facts and an objective description of the patient's current medical condition—that is, diagnoses, prognosis, psychological or mental status, and decision-making capacity. After compiling the data, the medical care goals are explored from the vantage point of the physicians and other medical care providers followed by formulation of the various options for treatment (or non-treatment) and similarly developing the goals from the patient perspective. After eliciting the medical care goals from the patient (or patient surrogate decision maker) all of the accepted options are presented to the patient (or patient surrogate decision maker).

The second phase involves discussion of the goals of care consistent with the patient's personal values and beliefs together with exploration of how to best achieve them. ¹³ The context here, for both physician and patient, is crucial: this intersection represents the greatest potential for conflict based on the absence of shared values. Patient circumstance may have significant influences based on familial relationships, socioeconomic considerations, or cultural implications including religious beliefs. Similarly, physicians (or other care providers) may bring their own value bias as well as acculturation of professional norms, legal ramifications, prior experience with similar clinical situations, or conflict with other clinicians involved with the patient's care.

The third phase of a systematic approach necessitates determining whether an ethical problem exists. This validation of the problem as first identified resembles the differential diagnosis in clinical reasoning that occurs after assembly of the discrete facts; however, in this instance, the inquiry addresses ethical rather than purely medical concerns, dealing with existing issues related to values, beliefs, and morals and, ultimately, the quality of life. At this stage, potential conflicting values should be identified.

The fourth phase in a systematic approach examines the context—that is, taking into account extrinsic influences beyond the confined physician-patient medical interaction. These might include legal ramifications, religious ideology, economic considerations, cultural heritage or customs, dysfunctional challenges within family units, or disparate perceptions between patient and caregiver. At this juncture, a prudent course of action may identify a clinical decision that has been rendered prematurely because this frequently represents a source of ethical problems; it may have occurred because of failure of the involved clinicians to obtain sufficient information to gain a full understanding of a patient's goals. This may require obtaining additional information from other sources; a need may exist to explore medical alternatives. The role of narrative mediation may assist in providing the beneficial insights through enhanced understanding of a patient's issues; physicians, nurses, social workers, and others on the health care team have different narratives of situations and different interpretations of the facts. Some ethical problems can be resolved simply by the additional information or continued dialog.¹⁴

Osteopathic Family Physicians provide added value to the bioethics conversation

The osteopathic family physician has unique skills and attributes that adds value to bioethics consultative teams. Within the core competencies in the Osteopathic Family Practice and Manipulative Treatment residency program requirements, required elements under *Professionalism* include:

- "a. demonstrate respect for patients and families and advocate for the primacy of patient's welfare and autonomy
- b. adhere to ethical principles in the practice of medicine
- c. demonstrate awareness and proper attention to issues of culture, religion, age, gender, sexual orientation, and mental and physical abilities"¹⁵

As osteopathic family physician residents graduate from their programs and gain the experiential advantages of practice, these skills will manifest as a strong contributor in the values-based bioethical conversations involving their own or other physicians' patients. This skill set is summarized in Table 2.

Although the preponderance of dramatic bioethical episodes have occurred in hospital settings, the examples cited in Table 1 demonstrate that the conversations increasingly will occur in alternate outpatient settings, particularly as technological advances with bioethical components continue to emerge. Table 2 shows an array of useful needed

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Table 2 Osteopathic family physician skill set for bioethics

- Extensively developed interpersonal communication and family meeting facilitation skills
- Experiential base is pragmatic, collaborative, and patient-centered
- Underlying education and training provides extraordinary appreciation of the conflict between the four goals of medicine: to cure disease, to promote health, to relieve suffering, and to prolong life
- Extensive knowledge and experience with scenarios across the human life cycle
- Significant exposure to cultural competency experience, with sensitivity to diversity, patient educational needs, and community health
- Ability to manage the complexity of physiologic issues, interpersonal conflict, and internal family conflict

skills and experiences possessed by the osteopathic family physician, regardless of setting. The hospital experience provides the greatest insights for future developments affecting this discipline.

Eighty-one percent of all US hospitals have an ethics committee or consultative service, with most facilitation provided by a subcommittee. Although committee (or subcommittee) composition may include various other professionals, the vast majority of consultations are physician- (94%) or nurse- (91%) driven. One area of concern, however, is that 85% of individuals administering the consultations lack any formal bioethics training. ¹⁶

In its present iteration, hospital ethics committee activity, in addition to the consultative service, includes development of policies and approaches to issues such as advance directives; do-not-attempt-resuscitation status; organ or tissue donation or transplantation; medical futility; and other noncurative foci on end-of-life, palliative, hospice services, or other aspects of terminal care; and the ethics education of committee and other staff members. In the best of circumstances, these are difficult conversations; what makes them more challenging is that these conversations frequently occur when a patient's condition deteriorates to an unanticipated degree of extremis rather than following the natural progression associated with chronic disease. Often the physicians caring for the patient at this juncture lack a longterm relationship that provides a level of trust and allows for candor. Across this continuum, the osteopathic family physician provides longitudinal care and can serve most effectively as facilitator or mediator in situations with profound bioethical implications. However, mastery of the discipline of bioethics consultation, mediation, or facilitation requires both cognitive knowledge and the ability to complete the associated behavioral tasks applying the values-based approach; this mastery includes expert competency and communication skills related to obtaining informed consent, discussion of the cessation of life-support therapies, use of palliative rather than curative interventions, planning for advance directives or living wills (including durable powers

of health care attorney), and, particularly, skills in conflict resolution.¹⁷

Although the bioethical dilemmas continue to unfurl, recurring themes undoubtedly will persist including quality of life, personal autonomy and decision making, dignity, media impact, public opinion and policy, family dynamics, health care and other socioeconomics, technology, intergenerational mode variance, cultural diversity, legal implications and social justice, resource allocation, and lessons from the historical context. Despite the evolving nature of bioethics, the paramount question for each individual patient, as well as for their physicians, was passionately articulated by noted bioethicist Howard Brody: "What, all things considered, ought to be done in this situation?" ¹⁸ It fits the credo of the osteopathic family physician and offers an opportunity to honor our heritage.

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