ARIZONA HEALTH FUTURES

BALANCING *ACT*
Ethics in Health Care

The Arizona Landscape

INSIDE

St. Luke's Health Initiatives
A Catalyst for Community Health

What Would YOU Do?

A girl is born with only part of her brain intact. She will never make a volitional movement the rest of her life. The family is on Medicaid, and they want everything done for their child. What is the right thing to do: keep her alive or let her go?

A 15-year-old girl is diagnosed with Crohn's Disease. Her parents are undocumented and have little money. The hospital gives the family a 30-day supply of necessary medications, without which she could die, then discharges her. Who will care for her now?

A 60+-year-old woman with a lung transplant contracts cancer and starts painful and protracted chemotherapy. She wants to end it – she says she "doesn't want to live this way anymore." Her family and her doctors want to press on. Who decides?

A man requests removal of his wife's feeding tube. She has been in a persistent vegetative state for one year. Her family vehemently disagrees. They think she may recover one day. What to do?

A woman comes into the emergency room to inquire into the condition of her mother, who is unconscious and bleeding as the result of a head-on collision. Both mother and daughter are Jehovah's Witnesses. The daughter produces a card signed by her Mother requesting that no blood transfusion be given, a fundamental tenet of their faith. What should the ER physician do?

You are a nurse at the bedside of a woman whose death is imminent. She asks you if her only son is on the way to the hospital to see her before she dies. You have just been informed that he was killed in a tragic auto accident on his way there. What do you tell her?

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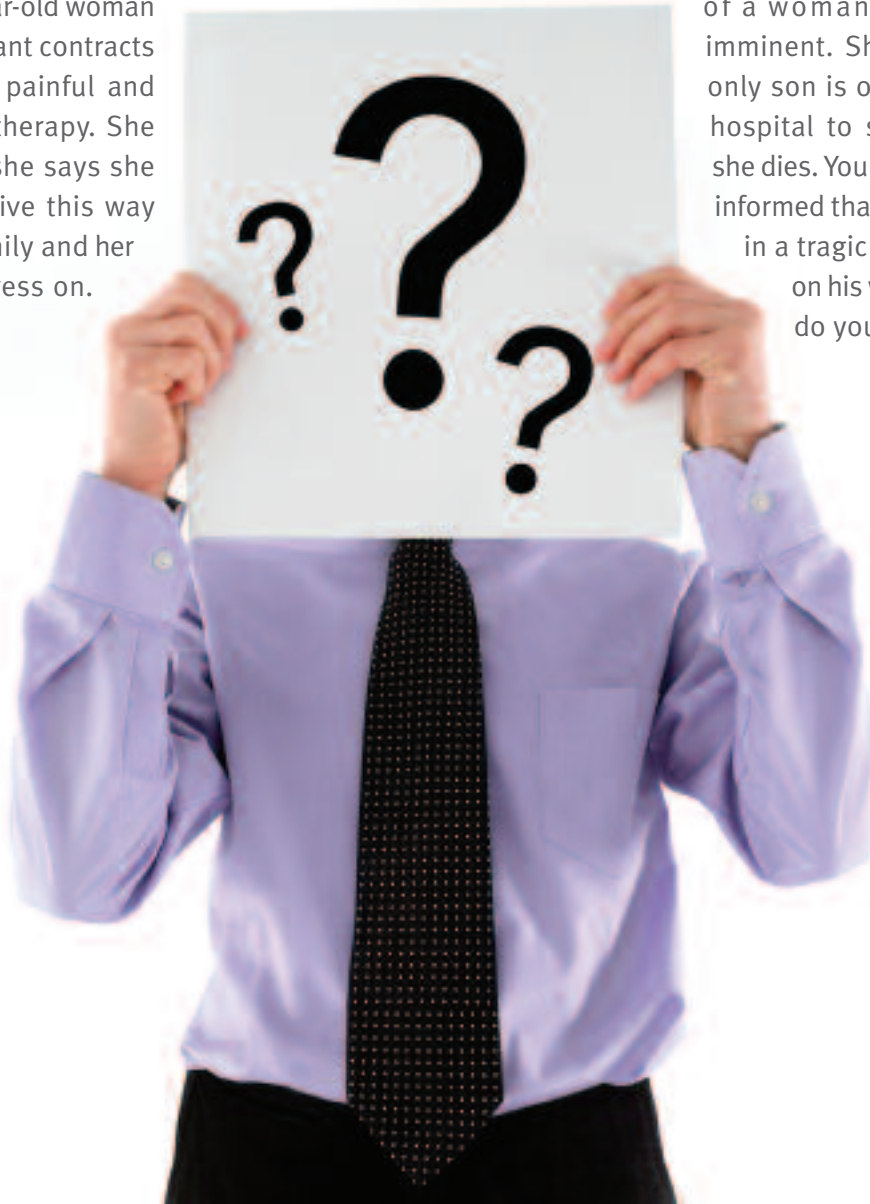
As these scenarios illustrate, health care is an exercise in *ethical* and *moral* judgment: clarifying, evaluating and making decisions about right and wrong, good and bad, acceptable and not acceptable in situations where norms of conduct, values and beliefs can come into conflict.

These are often matters of life and death, where rights and wishes of patients are weighed alongside the medical judgment of experts, the law, wishes and opinions of family members, issues of social justice, and public accountability for the allocation of scarce resources in the face of seemingly unlimited desires and needs:

- People demand the latest and greatest in health care treatment and technology. Are they entitled to it?

- In the face of major disability and infirmity, we can keep people alive for extended periods of time. Should we?

- Where does personal responsibility for health care leave off, and public responsibility begin – and vice versa?

- How far should physicians go today to accommodate the wishes of patients?

- Is it possible to practice ethical medicine in an unethical system?

Balancing Act

Health care is an ethical balancing act of monumental proportions. With millions of people uninsured, rapidly rising costs, disparities in access and outcomes, and an aging population expecting care to be there when they need it, the scale balancing unlimited perceptions of need on one side and limited resources on the other is brought into sharp relief.

Benefit of treatment is balanced with cost, individual autonomy and freedom with social solidarity and justice, the possible with the probable, the personal with the public, the needs of generations living today with generations yet to come.

What is **Ethics?**

As the term is commonly used, ethics is a set of rules, principles or standards of "right" conduct – what we *ought* to do in the face of moral choices we encounter in our lives. Whether we refer to medical ethics, professional ethics, organizational ethics or personal ethics, we apply these standards to help us prioritize our choices and values in various dimensions of social life.

As a field, ethics is a subset of philosophy that examines the genesis, justification and validity of the moral norms that govern our conduct. Stated simply, *ethics is the systematic study of the moral domain*. Morality, in turn, can be conceived as a social institution that encompasses specific rules, rights, principles, virtues and responsibilities that we come to understand and adopt as participants in a common culture.

Practical Ethics

Here, we are primarily concerned with *practical*, or applied, ethics: how we ought to examine and respond to moral choices in health care. For the most part, we limited our focus to moral choices clinicians face on a daily basis, and do not investigate emerging areas such as genetics and human reproduction, as important as they are. We also consider *normative ethics*, or deciding what moral norms of conduct to accept, and why. Theories and principles are starting points, but they must be supplemented with paradigm cases of right action, empirical data and organizational experience, among other practical considerations.[1] For our purposes, we don't delineate sharply between ethics and morality, except to note that ethics is the more general, inclusive term to refer to a wide range of moral choices and conduct, while morality is more often used to describe standards of right conduct for individuals and specific cultures, faiths and periods.

Most people have an understanding of what ethics and morality mean. They apply to duties, principles and rules of conduct in *relationship to others*. It's when principles of right conduct conflict in particular relationships that the confusion begins.

> "The first step *in the evolution of ethics* is a sense of solidarity with *other human beings.*"
>

How do people decide what to do in ethical dilemmas?

How ought they to decide?

Physicians, nurses and other health care professionals balance competing norms and values on a daily basis as they consult with patients and families on what to do. Politicians and policy leaders balance the interests of groups competing for a slice of the public pie. Each of us, in our own way, balances our wishes and desires with what we believe to be right and true, what we owe to ourselves, and what we owe to others.

Achieving balance in one's personal life is challenge enough. Achieving balance in a morally charged and contentious $2 trillion healthcare system, where literally millions of lives and livelihoods are at stake, is of a different magnitude entirely.

Ethical Dilemmas in Health Care

While politicians and pundits debate endlessly on how to reform the health care system to make it more effective, efficient and fair, health care professionals face ethical dilemmas on a daily basis as they work with patients and families to provide the best care possible in the face of finite resources, legal and regulatory constraints, and often divergent opinions on what is the "best" thing to do in any particular situation.

What are ethical dilemmas in medicine? Exactly how do people decide what to do in cases that may be emotionally charged and morally ambiguous? How *ought* they to decide? Are we resigned to live in a pluralistic society of moral relativism, or are there principles we can apply and reasons we can give that transcend particular places, cases and culture, and provide a common ground upon which everyone can stand to address ethical dilemmas in medicine?

These are questions we take up in this *Arizona Health Futures* issue brief.

Method

Balancing Act is a partnership with Bruce D. White, DO, JD, who is academic chair of the pediatrics department at St. Joseph's Hospital and Medical Center (SJHMC) in Phoenix. In addition to being a pharmacist, a board-certified physician and an attorney, Dr. White has had fellowship training in clinical medical ethics and directs the clinical ethics fellowship program at SJHMC. His 2007 book, *Drugs, Ethics and Quality of Life*,[2] is a highly regarded casebook on how to approach both legal and moral issues in health care and pharmacy.

Dr. White initially asked SLHI to support a survey on the use of medical ethics committees in Arizona hospitals and long-term care facilities in order to draw implications for future policy and practice. SLHI's Board agreed not only to support the survey, but also to expand it through interviews with key informants in the Arizona health care community and research from focus groups of physicians, nurses, social workers, clergy and others on how they approach ethical issues in medicine. The interviews and focus groups were conducted by Sharon Flanagan-Hyde, who previously collaborated with SLHI on its *Mind, Mood and Message* study in behavioral health. David L. Altheide, PhD, Regents' Professor in the School of Justice and Social Inquiry at Arizona State University, provided expert qualitative analysis of the interview and focus group transcripts to draw common themes and conclusions. More information on all project contributors is found on page 50.

SLHI assembled the work of these collaborators and a critical review of the literature on ethics in health care to produce this *Balancing Act* issue brief. We provide some working definitions, an overview of principles of ethics and approaches to decision making in clinical situations, findings from a survey of the infrastructure in Arizona health care facilities to resolve ethical dilemmas, and lessons learned from the real world experience of Arizona clinicians and others in addressing them. Finally, we conclude with suggestions for improving policy and practice.

Excerpted quotes from the interviews and focus groups are not attributed, except where noted, in order to protect confidentiality.

Clinical Ethics Workup[3]

All ethical judgments start from an examination of the facts at hand. These four topics are present in every clinical encounter and provide one way of organizing those facts.

Medical Indications

Consider each medical condition and its proposed treatment.

- Does it fulfill any of the goals of medicine?
- With what likelihood?
- If not, is the proposed treatment futile?

Patient Preferences

- What does the patient want?
- Does the patient have the capacity to decide? If not, who will decide for the patient?
- Do the patient's wishes reflect a process that is informed? Understood? Voluntary?

Quality of Life

Describe the patient's quality of life *in the patient's terms*.

- What is the patient's acceptance of likely quality of life?
- What are the views of the care providers about the quality of life?
- Is quality of life "less than minimal?" (qualitative futility)

Contextual Features

Social, legal, economic and institutional circumstances in the case that can:

- Influence the decision.
- Be influenced by the decision.

(e.g., inability to pay for treatment, inadequate social support, confidentiality laws)

Moral Principles[4]

A set of four clusters of moral principles provides a widely used analytical framework that expresses the general values underlying the common morality in clinical encounters.

Respect for Autonomy

A norm of respecting the decision-making capacities of autonomous persons.

Beneficence

A group of norms for providing benefits and balancing benefits against risks and costs.

Nonmaleficence

A norm of avoiding the causation of harm.

Justice

A group of norms for distributing benefits, risks and costs fairly.

Rules[5]

Moral principles are instantiated in rules informing practical action.

Substantive Rules

- Truth-telling, confidentiality, privacy, forgoing treatment, informed consent, rationing of care.

Authority Rules

- **Surrogate Authority** – who serves as surrogate for an incompetent person.

- **Professional Authority** – who can make a decision to override patient and/or family decisions.

- **Distributional Authority** – who makes a decision about allocating scarce medical resources.

Procedural Rules

- Rules for how we will decide: determining eligibility for services, reporting grievances, etc.

No one has ever set forth a system of moral rules free from conflicts, exceptions and alternative explanations. But that is no cause for skepticism. As moral agents, we face choices daily and must often choose between competing versions of the good.

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Virtues[6]

Principles, rules and rights are balanced in the cauldron of virtues, emotion and customs of moral agents in their daily lives.

Five Focal Virtues

- **Compassion** – imaginative concern and empathy toward others.

- **Integrity** – Soundness, reliability, wholeness and integration of moral character and judgment.

- **Discernment** – sensitive and acute insight, judgment and understanding in action.

- **Conscientiousness** – doing the right thing because it is right – conscientiously.

- **Trustworthiness** – belief in, and reliance on, the moral character and competence of another.

Emotion and socio-cultural customs round out a comprehensive vision of the moral life, and inform our relationship to others in ways that often transcend appeal to principles and rules. They, too, must be taken into account.

The Historical *Context*

Ethical issues in medicine go back thousands of years, beginning with the teachings of Hippocrates ("Do No Harm") and earlier, but it was within the past 50 years that rapid advances in medical knowledge and technology, coupled with rising consumer expectations and questioning of traditional sources of authority, seeded the fertile ground of bioethics:

- Medical culture moved from the dominant principle of beneficence and the physician as the primary decision maker (paternalism) to respect for the principle of autonomy for the patient as a person and an active decision-maker.

- In the early 1960s, people became aware of ethical controversies in the "rationing" of medical resources. For example, a Seattle hospital "God Committee" was accused of using measures of "social worth" to determine which patients should get access to new and scarce kidney dialysis machines.

- "Baby Doe" rules were promulgated in the 1980s to address issues of children born with serious birth defects who would have died in earlier periods. States were required to have in place procedures for addressing cases of withholding "medically indicated" treatment. Keeping alive extremely low birth weight babies with major health problems became a dominant ethical issue in medicine.

- High-profile cases (Quinlan, Cruzan) increased awareness of ethical quandaries in "right-to-die" and "treatment refusal" cases. By 1992, federal certification required hospitals and other health care organizations to have some type of medical ethics committee or similar structure/process in place to address end-of-life dilemmas and other controversies. "Death with Dignity" became a social movement; Oregon passed its own Death With Dignity Act in 1997.

- Hospice was introduced in the U.S. in the late 1960s. The best selling book, *On Death and Dying*, by Dr. Elisabeth Kübler-Ross, helped to bring the subject of terminal illness to the front of public debate. Gradually, the language of death and dying, along with terminal illness, was replaced by "end-of-life" and "palliative" care. Advocates moved from living wills to advance directives and health care proxies.

- Beginning with the creation of the Hastings Center in 1969 and the Society for Health and Human Values in 1970, the study of bioethics became more formalized and moved into schools of medicine and academic departments like philosophy and theology. Today, the American Society for Bioethics and Humanities has over 1,500 individual and institutional members. Formally trained "bioethicists" work alongside clinicians, researchers, educators and policy leaders in addressing ethical dilemmas in medicine and science.

Meanwhile, consumers fueled the industrialization of American health care, which grew from $173 billion and 7% of the GDP in 1971 to $2.1 trillion and 16% of the GDP in 2007. People demanded the latest services and procedures, and a major portion of the economy was organized to provide them – even when they were ineffective, unnecessary or futile.

This industrialization of health care changed core relationships. Patients became consumers, physicians became providers, medical care became a commodity. Economic *margin* began to crowd out social *mission*; issues of personal autonomy and economic capacity held sway over social justice and solidarity. Personal relationships and social capital were stressed by economic relationships and technological modes of production. Today, in the words of one Arizona physician, American medicine is a system of "strangers taking care of strangers."

"In the 'good old days' of the 1950s, doctors frequently performed 'one-step' mastectomies – breast biopsies followed immediately by radical surgery – without the patient's knowledge or consent. Why trouble the little woman, they said, when I can just tell her husband what I am going to do?"

From The Ethics of Bioethics[7]

"Fifty years ago, you might have seen more uniformity on particular ethics topics, plus there wasn't a whole lot you could do that was controversial or different. Today, not only is there so much more that can be done, but there is a lot of diversity of opinions based on backgrounds, roles, faiths, lots of things. It's much harder to come to consensus than it used to be."

family practice physician

Hospital Ethics Committees:
The Arizona Landscape

Background

The traditional dyad of the physician-patient relationship has clearly changed to a provider-client/consumer relationship that is mediated in the shadows of "strangers" – third-party payers, gatekeepers, case managers, lawyers, utilization reviewers, risk management assessors, medical specialists, administrators, discharge planners, social workers – whose roles and relationships are dictated both by the economic requirements of the enterprise and an impenetrable thicket of laws, rules and regulations.

It's not as simple anymore as sitting down with your doctor and deciding what to do in some kind of common sense way. Today, we convene *committees.*

The modern ethics committee has its genesis in the "God Committees" from the 1960s that decided who had access to a then limited supply of dialysis machines; institutional review boards (IRBs) that were required by the federal government to ensure that patients gave informed consent prior to taking part in some experimental therapy or medical research; the medical-moral committees of Catholic hospitals to ensure that treatment was consistent with Catholic teaching; and the previously mentioned case of Karen Quinlan (1976), where the New Jersey Supreme Court referred to an "ethics committee" to confirm the prognosis that Ms. Quinlan would not return to a "sapient state."[8] Since 1992, the Joint Commission on the Accreditation of Health Care Organizations (JCAHCO) has required hospitals and other health care organizations to establish organizational mechanisms for formulating ethics policy and addressing ethical conflicts. In hospitals, this is usually the hospital ethics committee.

The *Hospital* Ethics Committee[9]

Functions

- Provide ethical consultations ("consults") within the institution.
- Develop policies pertaining to clinical ethics (e.g., advance directives, withholding/withdrawing life-sustaining treatments, informed consent).
- Retrospectively review ethics cases.
- Facilitate education about topics in clinical and institutional ethics.

Goals

- Promote the rights of patients.
- Promote shared decision making between patients (or their surrogates) and clinicians.
- Promote fair policies and procedures that maximize good, patient-centered outcomes.
- Enhance the ethical knowledge, action and environment of health care professionals and institutions.
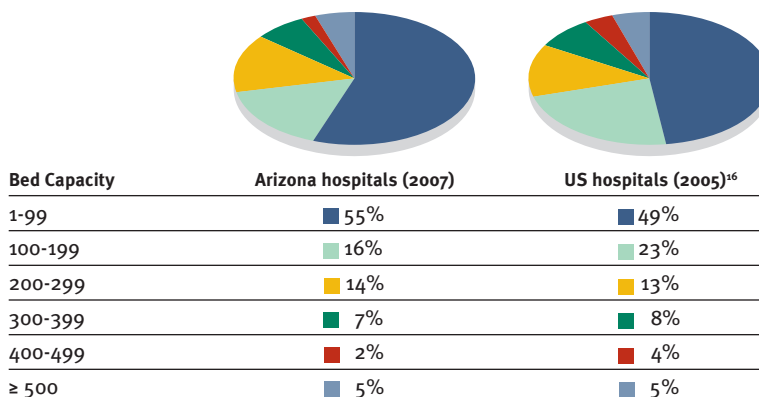
Membership

- Membership varies, but most committees include clinicians (physicians, nurses) from various departments, social workers, chaplains, lawyers, administrators and community representatives.

- Committees might also include someone formally trained in ethics (bioethicist), clinicians with some training in ethics, educators and others.

- Ideally, committee members are expected to be familiar with techniques of ethical analysis and the types of ethically charged issues generally encountered.

The Arizona Hospital Ethics Committee and Ethics Consultation Survey

According to the American Hospital Association, there were 97 hospitals in Arizona in 2007.[10] Table 1 compares Arizona hospitals classified by bed capacity with data collected by Ellen Fox, MD and associates in a survey of hospitals nationwide to learn more about institutional ethics mechanisms and ethics consultation services (the study was completed in 2001, but published in 2007).[11]

In addition to the Fox et al. survey, bioethics researchers have investigated the more general composition and work of hospital ethics committees in a number of state/regional surveys (Maryland, the District of Columbia and Virginia;[12] New Jersey,[13] and Upstate New York[14]) and one national survey.[15]

TABLE 1* ARIZONA, U.S. HOSPITALS BY BED CAPACITY

Bed Capacity	Arizona hospitals (2007)	US hospitals (2005)[16]
1-99	55%	49%
100-199	16%	23%
200-299	14%	13%
300-399	7%	8%
400-499	2%	4%
≥ 500	5%	5%

* Similar to the national survey, all small hospitals are not necessarily in rural areas. Some Arizona hospitals with less than 100 beds are specialty hospitals (e.g., heart, rehabilitation, long-term care hospitals) in urban and suburban settings.
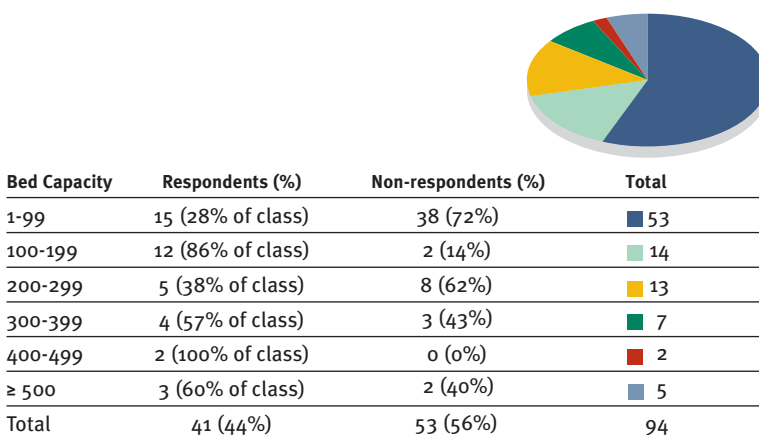
Arizona Survey Method

Under the direction of Dr. Bruce D. White, a St. Joseph's Hospital and Medical Center study team developed and implemented a 25-question, online survey to gather information about hospital ethics committees and ethics consultation mechanisms in Arizona hospitals in a format similar to the Fox national study. For the survey, 'ethics consultation' was defined as a service provided by a committee, team or individual to address ethical issues in a specific, active clinical case.

A study team volunteer contacted a person(s) at each Arizona hospital to identify the best informant for study purposes to answer the online study survey. Criteria for identification of the "best informant" were the same as for the Fox et al. national study – "the person most actively involved in ethics education, policy development and review, and consultation" within the hospital. Best informants included physicians, nurses, chaplains or pastoral care staff, social workers or case managers, risk managers, institutional administrative staff, medical staff secretaries and ethics committee chairs.

Thirty-one individuals responded to the survey representing 41 facilities. Five respondents represented two or more facilities that shared either

TABLE 2 ARIZONA SURVEY RESPONSE BY BED CAPACITY

Bed Capacity	Respondents (%)	Non-respondents (%)	Total
1-99	15 (28% of class)	38 (72%)	53
100-199	12 (86% of class)	2 (14%)	14
200-299	5 (38% of class)	8 (62%)	13
300-399	4 (57% of class)	3 (43%)	7
400-499	2 (100% of class)	0 (0%)	2
≥ 500	3 (60% of class)	2 (40%)	5
Total	41 (44%)	53 (56%)	94

clinical ethics committee membership or ethics consultation services. Table 2 provides an overview of response rates, classified by bed capacity.

Hospital Ethics Committee Survey Highlights

- Almost all (95%) of surveyed Arizona hospitals reported that they have a mechanism for providing ethics consultation. Of the two facilities that did not currently have an ethics consultation mechanism, one reported that they were in the process of developing an ethics committee.

TABLE 3 RATING THE GOALS OF ETHICS CONSULTATION

	Little/No Importance	Secondary Goal	Important Goal
Protection of patient rights			100%
Resolving conflict		6%	94%
Helping physicians deal with difficult cases		19%	81%
Educating staff about ethics policies and procedures		35%	65%
Educating staff about ethics issues		39%	61%
Increasing patient satisfaction	3	36%	61%
Providing moral support to staff		39%	61%
Suspension of medically futile/inappropriate treatment	10%	42%	48%
Reducing the risk of medical liability	16%	36%	48%

■ Important Goal   ■ Secondary Goal   ■ Little/No Importance

- When asked to rate the importance of various goals of ethics consultation, respondents unanimously (100%) rated "protection of patient rights" as an important goal, only slightly ahead of "resolving conflict" (94%) and "helping physicians deal with difficult cases" (81%).

- Facilities were more ambivalent about the issue of suspending medically futile or inappropriate treatment, with 48% listing this as an important goal. A combined 52% considered this either a secondary goal or of little or no importance. Similarly, "reducing the risk of legal liability" was seen as important by 48%, with the remaining 52% reporting this either of secondary or of little to no importance.
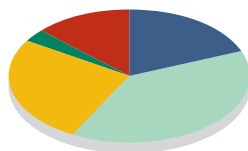
**TABLE 5
WHO PROVIDES ETHICS CONSULTATIONS IN YOUR HOSPITAL?**

■ Entire ethics committee	19%
■ Designated subcommittee/ consultation teams	39%
■ Individual ethics committee member	26%
■ Clinical ethicist/ consultant	3%
■ Other	13%
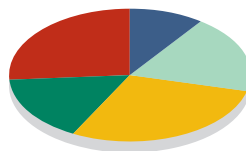
**TABLE 6
ETHICS CONSULTATION REQUESTS IN THE PAST 12 MONTHS**

■ None	10%
■ 1-2	19%
■ 3-6	29%
■ 7-12	16%
■ 13 or more	26%
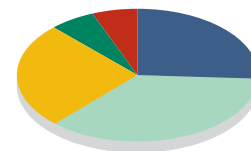
**TABLE 7
NUMBER OF PERSONS INVOLVED IN A TYPICAL ETHICS CONSULTATION**

■ 1-2	26%
■ 3-4	36%
■ 5-6	26%
■ 7-8	6%
■ 9 or more	6%
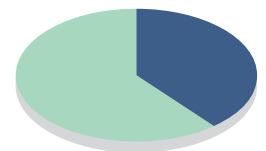
**TABLE 8
OPINION OF UTILIZATION OF ETHICS CONSULTATION SERVICES**

■ Underutilization	39%
■ Appropriate utilization	61%
■ Over utilization	0%

TABLE 4 ISSUES ENCOUNTERED IN ETHICS CONSULTATION (AT LEAST HALF TO ALL THE TIME)

End-of-life issues	91%
Family disagreement	68%
Advance directive issues*	61%
No available surrogate, proxy or patient guardian**	56%
Requests for medically futile or inappropriate treatment	52%
Determining a patient's decision-making capacity	46%
Palliative care issues	40%
Patient non-cooperation with medical advice	32%
Nurse-physician conflict	26%
Physician-physician conflict	16%
Unprofessional/unethical conduct***	10%
Perinatal/neonatal issues	6%

*   Conflicting directives, no copy of directive on the chart, family refusal to honor directive.

** To make decisions for an incapacitated patient.

***By physician or other care provider.

- It is curious to note that 52% of the consultation requests involved medically futile or inappropriate treatment when – in response to an earlier question (see Table 3) – 52% of respondents reported it as a secondary goal or of little importance.

- All respondents (100%) reported that anyone at their hospital (patient, legally authorized representative or surrogate, family member, physician, staff member) can request an ethics consultation.

- Over 77% of facilities reported that to their knowledge no one regularly involved in ethics consultation at their hospital had completed a fellowship or graduate degree in bioethics or related discipline. However, 68% reported that at least someone regularly involved in ethics consultation had direct training with a person experienced in ethics consultation.

- The majority of facilities (61%) do not require any specific actions or notifications prior to performing an ethics consultation, while 32% require notification of the patient's attending physician, and 29% require notification of the patient or patient's family or legally authorized representative.
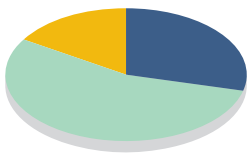

**TABLE 9
HOURS SPENT ON
TYPICAL ETHICS
CONSULTATION
REQUEST**

■ 2 hours or less	29%
■ 3-4 hours	55%
■ 5 or more hours	16%

Qualification: the survey did not specifically define what constitutes an ethics consultation request. Some facilities may have included informal (or "curbside") ethics consultations, while others did not.
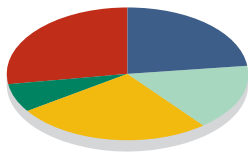
**TABLE 10
REGULAR MEETINGS
OF THE ETHICS
COMMITTEE**

■ Monthly or more	23%
■ Bi-monthly	16%
■ Quarterly	26%
■ Bi-annually	7%
■ As needed	27%
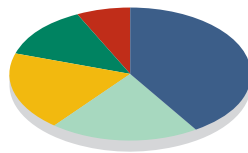
**TABLE 11
TIME SPENT ON
VARIOUS ETHICS
COMMITTEE TASKS**

■ Case consultation	41%
■ Policy writing/ review	20%
■ Community self-education	19%
■ Hospital-wide education	13%
■ Community wide education	7%
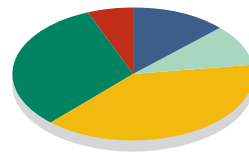
**TABLE 12
OVERALL LEVEL
OF AWARENESS OF
ETHICS CONSULTATION
SERVICES AT YOUR
HOSPITAL**

■ Low awareness	13%
■ Low/medium awareness	10%
■ Medium awareness	39%
■ Medium/high awareness	32%
■ High awareness	6%

- The most common reported means of gathering information during an ethics consultation are examination of the medical record and utilizing one-to-one discussions with clinicians involved with the case, with 94% reporting these actions as either "usually" or "always" occurring. Fewer respondents reported usually (36%) or always (39%) engaging in one-to-one discussions with the patient (or the patient's surrogate or family). Over 77% of hospitals reported utilizing group meetings with both clinicians and the patient, or patient's surrogate or family, in at least half of ethics consultations.

- There was a positive correlation between the perceived level of awareness of the ethics consultation service and its utilization, with 71% of respondents reporting low awareness and under-utilization, and a 75% correlation with a medium or higher level of awareness and appropriate utilization.

- By far the most common means of promoting awareness of the ethics consultation mechanism reported is through written materials placed in the hospital policy manual (94%). Slightly more than half of surveyed hospitals provide written information to patients about their service (52%). Even fewer facilities report posting information about their service for staff in patient units (42%), although nearly 49% report providing staff information in various hospital publications. Less than 17% report providing employee education about their ethics consultation service. The heavy reliance on written information for marketing purposes – hospital policies and patient information packets – may explain why 62% of surveyed facilities reported only a "low" to "medium" level of awareness of the hospital's ethics consultation service.

- The vast majority of respondents and surveyed ethics committees (73%) report that they regularly review their recent ethics consultations, though considerably fewer have either opted to conduct a formal review of committee effectiveness (19%), or to distribute a needs assessment to clinical staff about ethical issues (26%).

Rating overall effectiveness of hospital ethics committees and consultation services

- When asked to rate the overall effectiveness of the hospital's ethics consultation service on a scale of 0-10, the mode response was a rating of 6 to 7 (45%). Notably, 32% of respondents rated their consultation service's effectiveness even higher (8-10).

  - Most successful role of hospital ethics committees: ethics consultation

  - Less effective role of hospital ethics committees: staff and community-wide education

Preliminary Survey Observations

We will have more to say about hospital ethics committees in Arizona when we discuss the findings from interviews and focus groups. These are some preliminary observations:

1. No one thinks hospital ethics committees in Arizona are over utilized. While over 60% of respondents felt they were appropriately utilized, almost 40% felt they were underutilized.

   But why? The survey did not ask to whom clinicians turn for assistance in solving ethical dilemmas, nor why they don't necessarily look to ethics committees first. Other studies, however, shed some light: (a) Most often, clinicians turn to peers (physicians turn to physicians, nurses turn to nurses) for assistance in resolving recognized

ethical dilemmas;[17] and (b) clinicians may not think that ethics committee members or ethics consultation services have the necessary expertise or credibility, or that – based on knowledge from previous experience – ethics consultation services themselves are beneficial.[18] Table 13 lists some reasons why physicians are often hesitant to ask hospital ethics committees for assistance. All factors considered, it's reasonable to conclude that ethics committees might profit from better training and credibility within their own institutions.[19]

2. Survey respondents reported that protecting patient rights (100%), resolving conflict (94%), and assisting physicians in dealing with ethical dilemmas (81%) were the primary goals of their interventions (Table 3). Moreover, Arizona ethics consultation services/ ethics mechanisms reported that much of their consultative work involved end-of-life situations, perhaps one of the more extremely charged emotional periods for any involved that calls for great sensitivity and careful intervention. As we will see from the interviews and focus groups, one might wonder whether the services or mechanisms comprise the necessary qualifications and skills sets to be as effective as possible.[21]

3. In over half of the cases, clinicians have to deal with institutional and statutory responsibilities concerning incapacitated patients who have not identified a willing surrogate to participate in the treatment decision-making process (Table 4). Despite the recent attention paid to advance directives, health care proxies and the like, we clearly have a long way to go before people are comfortable enough talking about their own possible incapacity in these situations to make the necessary arrangements in advance – and to talk candidly and openly with their designated, willing proxy about how they wish to be treated.

4. In roughly half of the end-of-life issues or situation cases, the ethics consultation service or mechanism was asked to contend with medical futility or appropriate medical treatment concerns (Table 4). Only two jurisdictions (Tennessee[22] and Texas[23]) have statutory schemas for the resolution of medical futility or inappropriate medical treatment conflicts. Arizona hospitals and ethics services and mechanisms – without statewide regulatory guidance – are left to deal with inappropriate medical treatment demands (such as, the incapacitated patient's surrogate or family not honoring the patient's advance directive) or medical futility situations piecemeal.[24]

Most often, physicians turn to physicians for assistance in resolving recognized ethical dilemmas.[17]
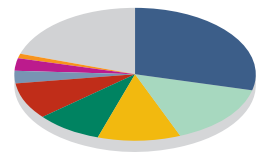
TABLE 13 REASONS WHY 41% OF PHYSICIAN RESPONDENTS WERE HESITANT TO ASK HOSPITAL ETHICS COMMITTEES FOR ASSISTANCE (2004)[20]

Too time-consuming	29%
Make things worse	15%
Unqualified [consultants]	11%
Unhelpful	9%
Offer solutions inconsistent with good practice	9%
Difficult to access	3%
Concerned about confidentiality	3%
Fear reprisal	1%
Other/Unknown	20%

Arizona (INSPIRIS)
Nurse Practitioners Survey

INSPIRIS of Arizona is a Nashville, Tennessee-based company that contracts with managed Medicare and Medicaid providers that have clients residing in 70 long-term care facilities and 22 assisted living facilities in the greater Phoenix area. INSPIRIS offers family and geriatric nurse practitioners (NPs) as primary care service providers in collaboration with contracted physicians. Under this program, nurse practitioners see the patients an average of once a week as distinct from the traditional fee-for-service model, where physicians are required to see patients every 60 days. INSPIRIS agreed to partner with the SJHMC study team to gather information about ethical dilemmas in selected Arizona long-term care facilities.

- The study team developed a 20-question survey instrument within an online survey tool and data collection system. In contrast to the hospital ethics committee survey, more of the questions were short-answer (maximum 150 words) and open-ended.

- Seventeen nurse practitioners completed this survey for a 47% response rate. All respondents except one were female. Over 82% of respondents were 46 years old or older.

- Because of sampling techniques and small sample size, no statistical analysis was done.

- The number of years of clinical experience as NP was evenly distributed, with 29% of respondents reporting 5 years or less experience, 24% with 6-10 years experience, 29% with 11-15 years experience, and nearly 18% reporting 21 or more years of experience.

hospice!

aggressive
treatment!

AHF

TABLE 14 THREE MOST TROUBLESOME ETHICAL DILEMMAS ENCOUNTERED IN THEIR CLINICAL PRACTICE
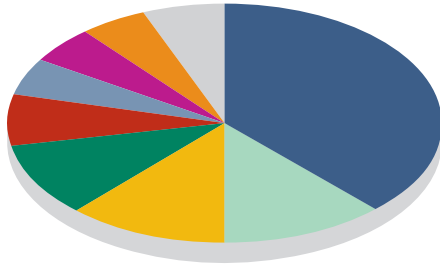
■ Family conflict over medical treatment plan (38%).
"Conflict between family members, one who is in denial of how hopeless a situation is, and the other family member who is ready for hospice, but the one who wants aggressive treatment prevails."

■ Advance directives not honored (12%).
"Families being allowed to change advance directives when the patient is no longer able to speak for themselves."

■ Insurance issues (12%).
"Receiving a call from a case manager for an insurance company telling me that my patient was being discharged from a skilled nursing facility, and that I had no choice in the decision."

■ Patient given inappropriate/inadequate treatment (end-of-life treatment) (10%).
"Multiple futile treatment patients receiving aggressive intervention."

■ No surrogate (7%).
"Patient without decision-making capacity, no legal surrogate, approaching end-of-life without advance directives."

■ Non-clinical staff directing medical treatment plan (5%).
"Lay persons dictating how medical professionals should be practicing."

■ Cultural/language barriers (5%).
"Cultural beliefs related to death and dying and overcoming my own personal bias."

■ Inadequate family support (5%).
"Family wanting to withdraw care on a patient who was not dying."

☐ Other ethical dilemmas (6%).
Among those mentioned: patients themselves requesting medically inappropriate end-of-life treatment; conflicts over whether to enroll patients in hospice; non-compliance with medical treatment plan; polypharmacy (prescribed multiple drugs, often unnecessarily and with adverse consequences); clinician conflict over plan of treatment and care.

NP Survey Highlights

- In an open-ended question, respondents were asked to identify up to three of the most troublesome ethical dilemmas encountered in their clinical practice over the past 12 months. Table 14, a list of issues with examples of responses, is presented in rank order of frequency mentioned.

- When asked to specify the single most troublesome ethical dilemma of those cited in Table 14, respondents identified 'family conflict over medical treatment plan' (50%). This was followed by 'patient given inappropriate/inadequate treatment' (13%) and all other dilemmas received less than a 7% response each (see Table 15).

- 69% of respondents reported seeking assistance from someone else in attempting to resolve their most troublesome ethical dilemma (see Table 16).
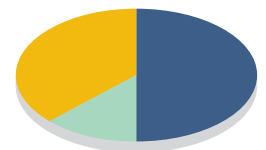
TABLE 15 MOST TROUBLESOME ETHICAL DILEMMA

■ Family conflict over medical treatment plan	50%
■ Patient given inappropriate/ inadequate treatment	13%
■ Other issues	37%

TABLE 16 SOURCES OF ASSISTANCE IN THE RESOLUTION OF ETHICAL DILEMMAS

Attending physician	73%
Supervisor	55%
Patient legal representative	46%
Social worker	46%
Peers	46%
Family members	36%
Consultant physicians	36%
Ethics committee member/consultant	27%
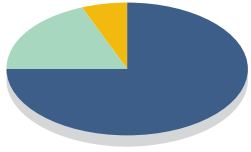
**TABLE 17
WAS THE ETHICAL
DILEMMA RESOLVED?**

■ No	75%
■ Unsure	19%
■ Yes	6%
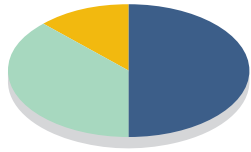
**TABLE 18
DOES YOUR
INSTITUTION
OFFER ETHICS
CONSULTATION
SERVICES?**

■ No	50%
■ Unsure	37.5%
■ Yes	12.5%
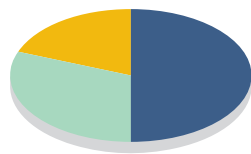
**TABLE 20
DOES YOUR
INSTITUTION
OFFER ETHICS
EDUCATIONAL
PROGRAMS FOR
THE CLINICIAN
COMMUNITY**

■ Yes	50%
■ No	31%
■ Unsure	19%

- 75% of all respondents stated that their most troublesome ethical dilemma was not completely resolved. Nearly 19% reported that they were unsure whether it had been resolved or not (see Table 17).

- When asked if their institution offers ethics consultation services, one half of respondents answered 'no' and 37.5% were 'unsure.' This may explain in part why only 27% of respondents sought the assistance of an ethics committee representative to resolve the dilemma (see Table 18).

- Table 19 shows how respondents identified topics that, if addressed, would be of the greatest value in dealing with ethical dilemmas that arise in patient care. Medical futility tops the list.

TABLE 19   TOPICS OF IMPORTANCE IN ADDRESSING ETHICAL DILEMMAS IN PATIENT CARE

Medical futility	75%
Determining decision-making capacity	75%
Informed consent and refusal	56%
Advance health care planning	50%
The role of culture, race, and ethnicity in health care	50%
Organizational ethics and compliance concerns	38%
Fundamental ethical principles	38%

- 90% of NPs reported that they usually attend educational programs for the clinician community. When asked whether these programs were beneficial, 55% reported "yes," while the remaining respondents said "sometimes," depending on the topic and presenter.

- Factors for attendance – or lack of attendance – of health care ethics educational programs were fairly expected, relating to topic and time (see Table 21).

TABLE 21 WHAT FACTORS WOULD MAKE YOU WANT TO ATTEND A HEALTH CARE ETHICS EDUCATIONAL PROGRAM? WHAT FACTORS WOULD KEEP YOU FROM ATTENDING?

WANT TO ATTEND

Important and/or interesting topic	75%
Convenient time and/or location	56%
Continuing education credits (CEUs)	38%

KEEP FROM ATTENDING

Too busy/too little time	90%
Uninteresting/overly general topic	40%
No CEUs offered	10%

Preliminary NP Survey Observations

- Not surprisingly, ethical dilemmas that occur in long-term care facilities are similar to those in Arizona hospitals (e.g., end-of-life care conflicts, assessment of decision-making capacity, informed consent quandaries, medical futility questions, and identification/authority of surrogates).

- Based on this study sample of long-term care facilities in the Phoenix metro area, very few of them have institutional ethics consultation services or mechanisms to deal with ethical dilemmas that arise in patient care similar to Arizona hospitals. The fact that almost 38% of respondent NPs were unsure whether the facility had such services is a good indication that, even where they do exist, they are not necessarily well integrated or utilized.

- NPs in long-term care facilities typically turn to physicians, supervisors and peers for assistance in resolving ethical dilemmas. This, too, is consistent with the hospital setting, where both formal and informal ("curbside") consultations occur between peers and others on the clinical team. It is interesting to note, however, that 75% of the NP respondents did not consider their most troublesome ethical dilemma to be completely resolved. One might speculate that ongoing communication and follow through among consultation participants are lacking, which is a subject for further research.

- Similar to results from the Arizona hospital ethics committee survey, the NP survey suggests that Phoenix area long-term care facilities and providers might benefit from access to trained, experienced clinical ethics consultants and targeted educational efforts in dealing with ethical dilemmas that arise within their institutions. This begs the question, however, of how such consultants and educational efforts are most effectively deployed, especially within the larger context of community and organizational culture, where roles, rules, values and relationships are forged through deeply embedded social norms, and are not easily changed.

Long-term care facilities and providers might benefit from access to trained, experienced clinical ethics consultants.

Ethics as Lived Experience:
Arizona Perspectives and Practices

If these surveys make anything clear, it's that ethics committees and consultation services are common in Arizona hospitals (less so in long-term care facilities), but are not necessarily as widely accepted and utilized as they might otherwise be with more members trained in analysis and mediation in clinical ethics, better integration into day-to-day clinical practice, more focused staff/community education on topics in clinical ethics, and strong institutional and clinician leadership.

But ethics in health care hardly begins and ends with medical ethics committees and formal consultation services. Ethical issues and dilemmas are faced daily by clinicians, patients, families and others as part of *lived experience:* one's biography, work and everyday life experiences in the care setting and larger organizational and community culture.

People bring different life experiences, attitudes, values, beliefs and expectations to the table: those who work in hospice are more oriented toward palliative care and communication with family members; nurses are more likely to see themselves as patient advocates; physician specialists may be more attuned to medical interventions based on expert knowledge; clergy are connected to spiritual issues; and so on. In myriad ways – and often without help from ethics committees or expert consultants – they come together to discuss what ought to be done in situations where wishes, values and beliefs may be in conflict.

Situational features such as time constraints and interpersonal relationships can greatly influence the way in which ethical decision making actually takes place. If we wish to get a more complete picture on how ethical issues are approached in medicine, we need to take this broader dimension of lived experience into account.[25]

Method

SLHI chose to augment the surveys on ethics committees and consultation services in hospitals and long-term care facilities with a qualitative analysis of perspectives, meanings and concerns from a theoretical sample of persons engaged in relevant positions and activities associated with clinical and medical ethics in Arizona. In addition to conducting 10 formal interviews with leading experts and others suggested by their peers as knowledgeable about, and experienced in, ethical dilemmas in medicine, we conducted four focus groups consisting of (1) ethics committee members, (2) physicians, (3) nurses, and (4) social workers, clergy and administrators/counselors, all of whom were involved in private practice, hospitals, long-term care facilities, hospice and related institutional connections.

All interviews and focus groups were audio recorded, and transcripts were produced. Topics included views of key ethical issues and dilemmas, the nature of ethics consultation in Arizona medical practice, and ways to improve the process and resolution of dilemmas in medical ethics in Arizona. In three of the four focus groups, a facilitator presented five medical ethics scenarios to help frame the discussion (see pages 21-22). Transcriptions were then analyzed qualitatively by ASU professor David L. Altheide to identify common themes and patterns. We take these up under the general headings of ethical dilemmas in context, perspectives on ethics, perspectives on ethics committees, and dimensions of ethical issues.

Medical Ethics Scenarios

Mr. L is a 75-year-old man in a long-term care facility. He has many chronic health conditions, including lung disease, heart disease and high blood pressure. His health has gotten much worse over the last few years. His wife of more than 50 years died two years ago. Mr. L has decided that he no longer wants to take any of his medications, and he no longer wants to eat. He's ready to die and has contacted hospice on his own. If you were involved in his care, what are the key issues that you see?

Mrs. S is a 70-year-old Hispanic woman who is in the intensive care unit after having a stroke. The doctors think she has no chance of recovering. The best case scenario is that she will have severe mental and physical problems. She needs full medical support. Mrs. S has a living will – but no medical power of attorney – that clearly states she would not want to be kept alive using a breathing machine or other medical means, if she is not able to be independent and carry out her daily activities. Mrs. S's husband is dead. She has five adult children who are all sure that a miracle will happen, and who refuse to allow a do not resuscitate (DNR) order or to discuss stopping treatment. Can the family override the living will?

BJ is a 14-year-old juvenile offender who sees his mental health therapist monthly as part of his treatment schedule and parole plan. He sees a psychiatrist every six months. At present, he takes a mood elevator for depression and a stimulant for attention deficit hyperactivity disorder. During a routine visit with his therapist, he draws several pictures as an element of his ongoing evaluation and treatment. His drawings today show a remarkably different pattern: one shows weapons, a handgun, an automatic rifle and a knife dripping with blood; another depicts an empty room. The therapist is concerned and has a conversation with her supervisor about what she sees as a change and the need to report these concerns to his psychiatrist, his parents and his parole officer. How do you think this should be handled?

more…

Ms. J, an 86-year-old female who was diagnosed with Alzheimer's disease 10 years ago, has been a resident in a long-term care facility for the past four years. She has declined remarkably over the past 18 months and is completely dependent upon family and staff for total care. She lacks decision-making capacity. She continues to eat with a lot of encouragement, but it may take as long as an hour to complete a meal, and she often has difficulty with swallowing. Three days ago, she choked while eating breakfast and was transported to the hospital's emergency department. After evaluation, the team learned that she aspirates all liquids and semi-solids. She holds food in her mouth five to six times longer than normal, and it takes a lot of encourage-ment to get her to swallow. The team agrees that she should be fed with a feeding tube placed directly into the stomach. Ms. J has two daughters who are cooperating in making medical decisions for their mother. She does not have a written advance directive. The daughters understand their mother's values and preferences regarding most issues, but have never discussed the possibility of artificial nutrition and hydration with her. Their choices are to consent to the feeding tube placement or decline it. What are the issues here?

Scenario #4

Mrs. B has just delivered a baby with Downs Syndrome. The child has a correctable heart defect and an intestinal blockage. The intestinal blockage needs to be repaired urgently – without surgery the child will die in a few days. Mr. and Mrs. B are both special education teachers and understand the lifetime challenges and the marked variability in mental and physical development for Downs Syndrome children. After reflection, the parents refuse to consent for surgical correction of the intestinal blockage. They are supported in this decision by all four grandparents and their church community. The neonatology team agrees to provide comfort care only. The primary care nurse at the bedside is visibly upset by the notion of not surgically correcting the heart defect and intestinal blockage, and giving the infant morphine for discomfort. She believes that if the child did not have Downs Syndrome, the parents would agree to surgical treat-ment. She discusses her concerns with the attending neonatologist and her supervisor. They tell her the decision rests with the parents. The primary care nurse ponders reporting this situation to the state's Child Protective Agency. What would you do?

Scenario #5

A H F

Ethical Dilemmas
in Context

"I don't recall having medical ethics when I went to medical school...but clearly our ability to sustain the living, damaged child, or the end-of-life care, the dialysis, all of that is far more available than it was 20 years ago, so people are confronted with [ethical] issues now more than they used to be. The other thing...is the very paternalistic aspect, the way medicine used to be practiced. We can recall the husband who would come in 30 years ago and say, 'if my wife has cancer, don't tell her, we'll just keep her comfortable, she doesn't need to know.' And it's hard to think back that this actually was a way of practice and probably wouldn't have stood up well in an ethics course, had one existed."

neurologist

Many of the interview and focus group participants linked their views about ethical dilemmas in medicine to the larger social context in which they live and work. Medical care was ethically simpler at a time when there were fewer possibilities and choices; one did what one could with what one had. The ethos of paternalism was dominant: Physicians made decisions about what patients needed and were entitled to, and there was little questioning of authority or the options. One participant referred to this as "barnyard ethics," the farmer decided what to do based on practical considerations, and that was that.

Today, things are more complicated ethically because there are many more choices, particularly due to technological advances, which themselves are often expensive and thereby require more choices about access and eligibility. It is more than a little ironic to note that in a historical period of relative abundance, medical care continues to be governed by a discourse and perspective of *scarcity*.

The other complicating factor, noted earlier, is the increasing dominance of the individual/patient/consumer in the traditional patient-physician dyad. Where formerly the physician took the upper hand in decision making guided by the principles of beneficence and nonmalificence, today it is often the patient who is the chief decider based on the principle of autonomy. This has fundamentally reset the boundaries for the shared resolution of ethical dilemmas in medicine. All of the interview and focus group participants were aware of the major shift in roles, attitudes and perspectives over the past 50 years. A significant number of them even regretted it.

Barnyard Ethics

"Years ago I heard of something called 'barnyard ethics,' which had to do with what the farmer and his hands and his family decided about how much to support this, that or the other, both for the animals and in fact each other. 'You can't carry the hay anymore, you can't work here anymore.' And you have to be very careful, because barnyard ethics can be completely driven by one individual. [Today] it can't be delivered or done by an individual [anymore]."

neonatologist
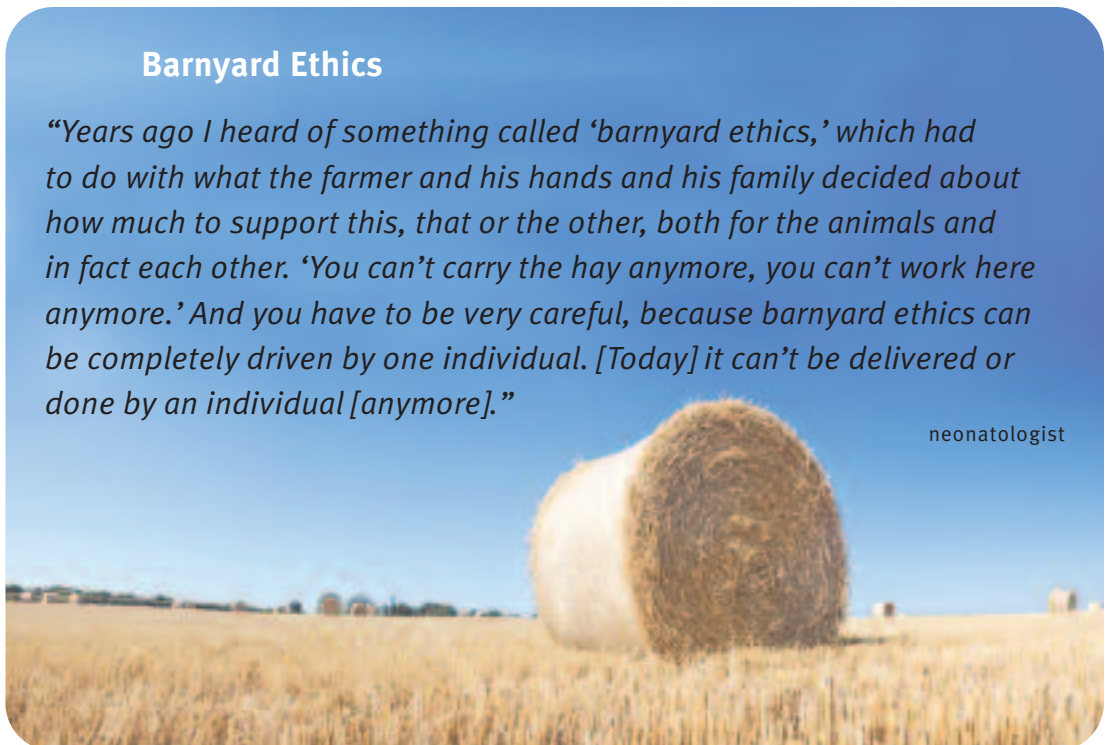
Perspectives on
Health Care Ethics

Our informants had differing perspectives on ethics and the span of ethical decision-making. As "lived experience," each saw ethical dilemmas in the context of their own experience, roles, relationships and organizational culture, as well as from the application of ethical principles in the process of moral reasoning. Some brief perspectives of physicians, nurses, social workers and clergy follow.

Physicians

Science Will Save Us

Many of the physicians we talked to commented that they learn more about ethical issues in medicine from mentors and personal experience than from attending seminars and reading journal articles. They also were acutely aware that mass media are part of the social context that shapes patients' perceptions about expectations in difficult medical situations. The dominant cultural narrative in our technologically driven society is that "science" will save us. If we can't solve the problem today, surely a medical breakthrough will solve the problem tomorrow. In the words of one physician:

> *"You know, Hollywood makes, relates history. There is always the old-time movie where somebody is sick and so forth, and all of a sudden, the doctor says, 'Well, there's this man in New York. If only we could get this patient to New York.' So advances are made, and the result may be fortuitous, but there is always a plan on how to attack the problem."*

Another physician commented on how television shapes patients' exaggerated expectations:

> *"You look at ER [the TV show], you look at it straight up, and you see that every time they do CPR on ER or Grey's Anatomy, 90% of them survive. Where, in reality, less than 1% survive. So you are setting this up, they've got an ambulance and they're doing CPR, and they'll probably do okay, when that's not true. They're dead."*

It's this take charge, can-do, science-will-save-us attitude that permeates ethically-charged clinical encounters and shapes the choices – both realistic and unrealistic – that patients and clinicians must make.

When to Start, When to Stop

Physicians provided a range of meanings about the scope of medical ethics, from important care decisions such as "when to start," and "when to stop," to ethical issues embodied in managed and fragmented care delivery. One physician, who consults regularly on ethical dilemmas in medicine and chairs a hospital ethics committee, provided an important critical context:

> *"Physicians, nurses and others in medicine are trained to think of everything as a medical problem that can be solved by the scientific method or intervention. Very, very slowly, people are starting to recognize some things are ethical and some things are medical, and some things are legal, and some things are beyond that in social policy…So the first thing I ask when I get an ethics consult is, 'what is your ethics question?'"*

The dominant cultural narrative in our technologically driven society is that "science" will save us. If we can't solve the problem today, surely a medical breakthrough will solve the problem tomorrow.

This same physician went on to provide a working definition of 'bioethics':

> "[Bioethics] is what governs the relationship between the physician and the patient that isn't dealt with under the black letter law…[it's] when to stop, when to start [treatment]. Those are the two big issues we always deal with. There's the privacy issue. There's can this person decide…it's okay to die. Decision-making capacity, not competence. [Competence] is something for the medical board in one sense and courts in another sense, but decision-making capacity often comes up in bioethics."

For other physician participants, especially those with less training and experience in ethical consultations, the scope of medical ethics was more diffuse. They were inclined to see it as an ongoing process, a feature of putting the welfare of patients first while also factoring in the increasingly autonomous orientation of patients with an eye toward the defensible use of resources (e.g., reluctance to perform a kidney transplant on an elderly and failing patient). Even though the scenarios presented were focused on clinical encounters specifically, many respondents quickly broadened the scope by voicing their frustration with having to practice in what they perceived to be an inherently unethical health care industry. They didn't want to limit the discussion to the clinical encounter alone.

On the other hand, some physicians clearly saw the ethical dilemmas in the broader healthcare system, but felt this was not their primary concern. In the words of an ER physician:

> "Sometimes you can purposely run up their [patient's] bills so they qualify for emergency AHCCCS by doing emergency CT scans and MRIs. But I have to look at it from a patient advocate perspective. That's not an [ethical] dilemma for me at all. We do the right thing for the patient, which is the wrong thing for the public. I'm not a public advocate, I'm a patient advocate."

What's Ethical, What's Legal

Several physicians spoke to what they perceived to be a conflation of the ethical with the legal, and how hospital ethics committees were often more oriented to issues of legality and avoiding litigation than focusing on ethical principles. In the words of one physician:

> "Very frequently, ethics committees get driven by the institution, and so a lot of things that would be ethically appropriate cannot happen in institutional health care because they have lawyers looking over their shoulders. And lawyers are a part of the ethics committees. So we don't necessarily do what's right ethically. We might have to do what's right legally, within society's boundaries, so they [ethics committees] are constrained."

For other physicians with experience and training in ethics consultations, the confusion between the domains of ethics, the law and social policy/practices was the result of lack of education among members of hospital ethics committees. The lines were clearly drawn – people just needed to be educated to distinguish between them:

> "Basically, it's the education. The education has to be done. It's most effective if it's local, but you first have to have the people educated to do that. There are very few people trained in bioethics in the entire state. There are a few physicians who are really well trained and have experience with bioethics committees, but they are training a handful [of others] at best…"

"On my side of it, where I work, I don't have a clue what the [financial] charges or costs are. I just do what I think is right, and it just spins away day to day."

physician intensivist

Conflict Resolution

Another physician perspective on ethics consultation in medical settings stressed the primacy of conflict resolution and avoidance:

> *"It [ethics consultation] is never about patient care, usually. By far, the most common consult when I was on the ethics committee was conflict resolution, and the most common recommendation was either to get another opinion or recuse yourself from the care of the patient, because you can't continue to handle it in this stressful situation, and please try to find another doctor or we will help try to find another doctor to take over the case."*

The emphasis on conflict resolution was mentioned by other clinicians as well. For example, nurses, social workers and clergy all mentioned conflict between family members and between family, patient and clinicians as a chief topic of discussion on ethics committees and in the informal "curbside" consults of daily clinical practice. This is consistent with studies that posit conflict avoidance and maintaining the integrity of the physician and entire clinical team as the principal motivators in the face of ethical difficulties, for which formal ethics consultation is often perceived to be a court of last resort rather than a primary source of assistance.[26]

Nurses

Patient Advocates

A clear message from the interviews and focus groups was that nurses are the ones who often obtain relevant information on the ethical dilemma in question, provide comfort, conversation, support and encouragement to all the parties involved, and are more likely to play the role of patient advocate than other clinicians. A physician and ethics educator explained:

> *"In the emergency department, especially in the ICU, what I see is that nurses are often times the patient advocate. They see the big picture over a long period of time, and they are the ones who raise issues. That's good, so if emphasis was placed in the right places – not to nursing, but to ICU nursing, for example – that would be very useful."*

The role of the nurse as patient advocate even transcends physician-nurse conflict. In the view of one nurse,

> *"I've had doctors who have been very upset at nurses who take the initiative and talk to the family about end-of-life issues. Some doctors feel like it's not the nurses' job, and I have to remind them that we are the patient advocate, and we have to do what we feel is right for the patient."*

In a similar vein, nursing practices that promote clinical ethics may not always be in sync with physicians' perspectives about appropriate conduct, including "prognosticating," or discussing a patient's future condition. The potential conflict between aggressive medical treatment and palliative care came up on several occasions. As one nurse explained:

> *"At the bedside they [nurses] recognize those issues sooner than the physician may, and then the physician writes an order that the nurses view as not within the patient's rights or within the patient's interests. That's creating conflict at the bedside, more so because maybe the physicians aren't taking as much education on end-of-life and palliative care as the nurses, so there is this void between those two groups."*

In Touch With Families

Many nurses spoke with passion on their role in getting to know the family situation, and how understanding those relationships can add insight and value into resolving ethical dilemmas in patient care. In all of the ethics scenarios presented for discussion (see pages 21-22), the nurses invariably asked for more information about the feelings and relationships of family members and others before they rendered a judgment. For example, in Scenario #4 – the elderly Alzheimer's patient who had difficulty swallowing food – one nurse commented:

"We need to talk to them [family] about their values and her [patient's] values regarding end-of-life issues, and there are some great resources out there to help families with those types of questions when somebody has dementia, and at what stage feeding is appropriate…So, to me, the issue is, where are the daughters in the relationship with their mother, and is this horrifying to them, or is this wonderful and great? That is what I want to know, because the only way you are going to make an inroad into that situation is to find out what the daughters are feeling."

Nursing informants suggested that educating and working with the family members can help them accept the decision to let the loved one go, especially if the patient has an advance directive. One nurse explained:

"It's not their [the family's] decision. You have to get consults where the nurse or physician goes to the power of attorney for decisions when the patient has made their decision in their living will…the patient has told you what they want. So if you muddy the waters by approaching that power of attorney and leading the family to think that they can make a decision, then you have to go back and correct that…You need to be real careful not to go down the road where they think they have decision-making power when they don't. I have found the family to be greatly relieved, because they believe when they make that decision, they kill that person, but the decision has already been made."

What if No Family Members are Available?

A number of nurses raised situations where family members are not available to help sort through ethical dilemmas in the patient's care, and the difference in how those situations are viewed today compared to the past. A nurse recalled:

"I've been a nurse for 30-some years, and it seemed like way back when, if you didn't have family, the doctors would make a decision for a code status and stuff. Nowadays the doctors don't want to make that decision. They want the families involved. So if they don't have families, they'll want the ethics committee to get involved. In our hospital, the ethics committee doesn't make decisions, they give suggestions and input, that kind of stuff. So it's a problem."

Do No Harm

For many nurse informants, the ethical imperative "Do No Harm" came down to an emphasis on relieving pain and making the dying patient comfortable, as distinct from more aggressive medical treatments designed to keep people alive whose natural systems were failing them:

"Most lay people have no idea what the risks and benefits [of medical interventions] are. That's our job. Research has shown that people who are in the dying phase, cognizant or not, withdraw from food or fluids, whether it's intentional or because they can't mechanically do it anymore. It's almost a God-given mechanism, because when you are a little bit dehydrated and malnourished, your cells are desensitized to pain. If they are hydrated and nourished, they are very sensitive to pain. It's really God-given. We need to tell them [the family] that. We need to let them know that we could be instilling a lot more suffering by inserting tubes."

"One time we had a patient who went five days being brain dead. The physician said, we're doing this because we're waiting for a family member to come in. He wouldn't deal with it."

ICU nurse

Once again, "Do No Harm" translated into an clear preference for palliative care, which many nurses viewed as an ethical requirement of good patient care. In the words of a hospice nurse:

> "I would like to see us go more to a palliative outlook where we could start sooner in the hospitals, start sooner in getting the patients on board to give them that support. I would like to see that education happening, and we are working on that."

However, like their physician colleagues, nurses were acutely aware of the ethical quandaries in the larger healthcare industry, where the ethical imperatives of beneficence and nonmalificence come into direct conflict with the economic imperatives of the "bottom line." A nurse practitioner at a long-term care facility put it starkly:

> "There is an ethical issue with regard to revenue. As a nurse practitioner, I have been literally forbidden to use the word 'hospice' or to talk about end-of-life care because they want everyone prolonged to generate revenue for the facility. It's all revenue-driven these days. That's not right."

Social Workers/Clergy

Intermediaries with Family and the System

Social workers and clergy contribute to patient care, support and emotional well-being, but they also help families to understand both routine and dire circumstances, as well as serve as important intermediaries with insurance companies, hospitals, and other social service agencies. They bring an important perspective to ethics committees, and several informants discussed their roles and contributions to patient care. As a physician explained:

> "They play a key and vital role, especially social services and case managers, because they seem to know not only just the patient but the family."

Within the hospital itself, social workers often serve as advisors and mentors to critical care staff, and help them to sort through difficult ethical choices. According to a social worker in a hospital managerial role,

> "Staff members for the most part will go to myself, as a department manager, or to other managers in their areas. There's a comfort level – we understand the jargon, we understand the situations they are in."

Undocumented Patients

Social workers in hospitals often find themselves having to navigate the turbulent ethical waters of providing care to undocumented patients. One social worker described a growing problem:

> "Immigration is a huge issue. Federal law says we have to take care of people until they are medically stable, and we have to have a safe discharge plan. Often, we need to send patients back to their home country if they are not in the country legally. [Points to files on desk.] This man is on a ventilator and being sent back to Honduras. The hospital in Honduras won't accept him unless we give him his own ventilator. So I have a bill here for the ventilator, and the Air Evac flight. We're going to pay that so that he can be safely discharged. I have bills here for $41,000."

Spiritual Support

Spiritual support is often a feature of clinical care, and clergy play an important role both in the direct provision of that care and in helping patients, families and clinicians

Clergy's capacity to tap into family members' meanings and priorities can contribute to patient dignity and family satisfaction with the treatment of their loved one. Such skill can bridge the gulf between science and religion, between home and an imposing hospital room.

bridge differences of opinion on how to address ethical issues that arise during the course of care and treatment. One pastor described the role clergy play in commenting on Scenario #2 (page 21), where family members are unwilling to accept their terminally-ill mother's living will:

"In the case of Mrs. S, if she was unable to communicate, I would still meet with the family privately and try to get them on board with her decision, and as a minister, speak to them on eternal value, the eternal nature. No offense, but doctors have their roles; nurses have their roles. But if a doctor says to the family, 'We're going to pull the plug,' that's not the same as if the minister says, 'We need to pull the plug.'…I would have counsel with a minister, a chaplain, in a warm, friendly, wonderful kind of way, with the Scriptures and the hope of eternal life and all these things, and bring the family on board [with their mother's wishes]…Then the doctors and nurses don't have to fight the family. It's already been done. To me, that's one of the best ways to handle it."
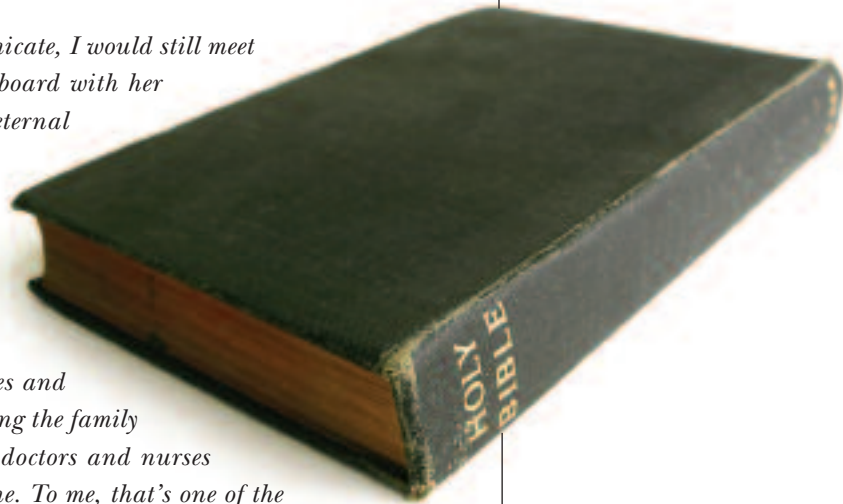
A physician in another focus group echoed some of these sentiments in his account of how he worked with the chaplain to assist with religious people who were near death:

"When we had a problem, instead of calling the ethics committee, we called the chaplain, because the chaplain helped us to get the autopsy permits. They prayed with the patients. They read the Bible. They always helped, because we're respecting this person's humanity. We [doctors] are noting that not everything is in our hands. We're not playing God. We're not just there to do things because that's what we do as doctors, but we're there to take care of the whole person, and I think that sometimes with all of these ethics committees and academic things, we're losing sight of that, what death really means to these people."

Clergy's capacity to tap into family members' meanings and priorities can contribute to patient dignity and family satisfaction with the treatment of their loved one. Such skill can bridge the gulf between science and religion, between home and an imposing hospital room. A minister described how he worked with patients and families:

"We have tried to get emergency data on our parishioners, such as who can I contact, or 'Where are your children?'…If one of them has medical power of attorney, I might say, 'All right, here's what we're seeing from dad. I just want to let you know what he's thinking and talking about doing, because you need to be aware, rather than surprised and blame somebody. Let's all of us get together and talk this over.' If he's in long-term care, if there is a social worker attached to the long-term care facility, let's get them involved. Let's get the support community involved."

A Low Blow

Despite agreement on the important role clergy play in addressing ethical dilemmas in clinical care, several of the respondents remarked on the perception that clergy don't play as prominent a role in the health care institutional setting as they once did. One respondent pointed to what he took to be tangible evidence of the trend:

"Some hospitals don't even have parking for clergy anymore. I mean, that's a low, low blow."

The Importance of
Bioethics Leadership

Kenneth V. Iserson, MD recently retired as Professor Emeritus of Emergency Medicine at the University of Arizona, where he also spent 25 years as Chair of the UMC Bioethics Committee, edited a highly regarded text, *Ethics in Emergency Medicine*,[27] helped write Arizona law governing advance directives, and consulted widely with hospital ethics committees.

For Dr. Iserson, it all comes down to *bioethics leadership* and having *proactive bioethics policies* in place to govern behavior. The following excerpts from his interview provide a critical context for thinking about ethics in clinical medicine and the role of ethics committees:

Q: **What do you see as the key ethical dilemmas in emergency medicine?**

A: It's no different than anywhere else in clinical medicine. It's recognizing there is an ethical issue involved. That's by far the biggest ethical problem… It's identifying ethical issues, and identifying that it really is an ethical issue.

Q: **Where are the unmet needs in Arizona surrounding ethical dilemmas for clinicians?**

A: There is a dearth of bioethics committees that are functioning like they should. There has been inadequate education, and not just education about ethical components, which by themselves are difficult enough to learn, but there is a dearth of leadership within ethics committees. I have consulted in a few cases for bioethics committees, and they were generally disasters. They were run by people who had no clue how to be group leaders, had no idea what ethical dilemmas involve, had no idea about problem-solving, had no idea about involving patients or families, and were operating strictly under a medical model, which is awful.

Q: **How do we improve education in bioethics?**

A: Well, you don't need to have all of these little conferences, because those are kind of useless. It's better to educate folks as cases come up, like the cases where we had more members of the bioethics committee coming in, and also invited the medical students, and the residents, and the social workers, and the nurses, and all family to sit with the committee. We'll discuss the issues, and then they get feedback, and so they learn about it that way, and it's very effective.

Q: **Are there specific areas where we need better education? For example, what about advance directives?**

A: The biggest problem there that we see [in emergency medicine] is nursing home patients, long-term care facility patients who don't have them [advance directives]. There should be greater use of do-not-hospitalize forms. It's okay for nursing home patients to die in the nursing home if there is nothing that can be done other than to prolong their death. And that is just not being done often enough. We need more education in that area, but turnover in skilled nursing facilities is so great that it's probably very difficult. So they need strict policies of some kind that will mandate behavior. You have to look at the front of the chart before you call the ambulance, and you have to put the advance directive on the cover of the chart in big letters. It has to say, 'Do Not Hospitalize.'

Q: **So education is not the only key to better addressing ethical dilemmas in clinical medicine. You need policies, too.**

A: Yes. Books, articles, conferences, those are fine, but that's not where education comes from. Education comes from bioethics leadership. The other key is proactive bioethics policies that will mandate the [ethics-based] behavior. Everybody in medicine says, 'education, education, education.' That works when I'm teaching people how to manage diabetic ketoacidosis, but even there I'd rather have them work from a flow sheet. Ethics is much more difficult than handling diabetic ketoacidosis or trauma, and yet many people try to do it by the seat of their pants. It doesn't work.

Perspectives on
Ethics Committees

Most of the interview and focus group participants had participated in various informal ethical consultations in their respective organizations, but there was wide variability in terms of experience with formal ethics committees and opinions on the role they play – or ought to play – in addressing ethical dilemmas.

The Need for Structure

Most participants perceived the work of ethics committees as well meaning, a bit daunting, and somewhat bureaucratic. Administrative functions were served, but overall benefits to patients and staff were more anecdotal and filled with potential than structurally sound. Part of the challenge was the diversity of views about the dimensions of ethics–including where clinical ethics begins and ends–as well as traditional medical culture that situates control and authority in the hands of physicians, who, in varying degrees, may expect more autonomy than ethics committee guidelines stipulate. One former ethics committee chair, a neurosurgeon, put it this way:

"My pet peeve is the fact that everybody feels they have an innate right to know what's right and what's wrong, and feels that they are doing something good, and those are the standards by which they judge their activities and their decisions, when in fact, there is a structure that you can use to make ethical decisions, and I would tell you that it's ignored universally. It's all about what feels good, what you think is right and what's wrong. I think that somehow we need to get the word out that there is a hierarchy of decision-making for others. There are ethical principles on which you have to make decisions, and I try to make people say, okay, what is the ethical principle on which you are making this decision, and I don't see that."

Another participant stressed the importance of organizational support and resources:

"It's been my sense that for an ethics committee to really function effectively, it needs to meet periodically and have dialogue. You can't wait until a crisis evolves and meet that week. You have to have dialogue leading up to that so that participants can look at the different backgrounds and approaches to issues, and it's only with that sort of structure that I think the ethics community can function effectively."

Others agreed, and noted the importance of multi-disciplinary perspectives on the ethics committee and an organizational commitment to dialogue:

"Clearly having the multidisciplinary participation is essential and then the committee has to meet regularly…so that the doctors and the nurses and social workers and the chaplain and various players get to know each other and can communicate before they really have an issue to resolve."

The Need for Education and Training

A number of clinicians commented that ethics committee members – and clinicians generally – lack the resources, training and mediation skills to resolve disputes and address dilemmas in a timely and effective manner. The notion that a request for help is akin to calling in the "ethics police" is grounded in a dominant culture of medical intervention and treatment. In the words of a pediatrician:

"A lot of us [physicians] don't have the greatest training in ethics. We were taught to fix things, and that's what we feel comfortable doing."

Ethics education was an important theme, not only in achieving a better understanding of how to approach and resolve ethical dilemmas, but also in developing proactive organizational policies that inform behavior. Some representative comments:

"Hospital policies. You get them in place, very straightforward, very easy to understand. It takes time to work through the bioethics committee, but then that's why a lot of smart people from diverse backgrounds will work through it for a year, and then come up with maybe a partially imperfect [policy]. But they get it, and then it's disseminated and people really get it, and all of a sudden those issues go away."

"Nursing leadership has to be…regularly trained in those [proactive] policies. That is one way of getting this out…I'm a big believer not in saying that we want to change behavior, but in figuring out the best way to change behavior."

One physician thought Arizona needed a medical ethics education forum:

"There needs to be a forum, and it needs to be a continually funded forum, and [we need to] get the managed care organizations to realize that funding a third-party forum probably ends up saving them in costs."

The Need for Time

Again and again, participants gave eloquent testimony to the pressures of working in life and death situations, and how the formal mechanisms of dealing with ethical dilemmas are often out of sync with the immediacy of events. A NP in an ICU unit described the problem succinctly:

"People get toasted in the hospital about futile care, the over utilization of resources, things like that. People need debriefing. They need someone to hear them, to empathize with the situation. That takes time, and time is something you don't always have."

The comment to the right agrees, and notes that the work of ethics committees often has more to do with creating the space and time for communication than issue resolution.

Most Ethics Committees are not "Mature"

Outside of a few programs, participants felt that most ethics committees provided few consultations on an annual basis and were not really "mature." One person explained how most of these committees functioned:

"I think it [ethics committee] needs to mature as a committee to really make a difference for folks. . . You need a committee that actually sits down with staff and really hears them out. Right now, a physician – somebody -- comes, gets the information, brings it to the physician on the ethics committee. He comes, maybe talks with a physician or two, maybe a family member, writes a recommendation and that's it. They staff it as a committee after the fact, retroactively, and that doesn't necessarily serve the here and now."

A Fully Functioning Committee

On the other hand, several of the participants were members of a more mature hospital ethics committee and described how institutional support, including access to a trained bioethicist, was integrated into medical practice and routinely called upon by caregivers. This particular ethics committee is staffed and supported by colleagues, and helps to enrich an organizational culture that values ethics as part of medicine. In the words of one of its members:

"A large proportion of the consults in ethics committees are not necessarily ethical issues, but facilitating groups of people who are responsible for care, resolving their perceived differences and bring them together to some common understanding. This takes time."

neonatologist,
commenting on
"The Need for Time"

"We meet monthly. They have started an ethics fellowship. This is our second fellow. It was one year, but this particular fellow is here for two years, so since that fellowship has started, it's taken on a whole new level because the fellow can be available for more consults. Because someone is always there, and the awareness is there as she goes up and down the hospital. So we average about 6 to 10 consults a month. And some of them are just communication issues. They initiate an ethics consult, but when we talk to the family or to the team initiating it, when we say what's the ethical principle, there isn't any ethics involved, it's just kind of communications. The specialist wants something, and the family wants something. We mediate and talk, and have a family meeting and resolve issues about who is going to speak for the patient and what's appropriate, that kind of stuff. So it varies."

However, this committee was an exception. There was a strong consensus that most ethics committees in Arizona were not as well staffed, prepared, or utilized as they should be.

A Minority View

A minority view expressed was that the ethics committees were not always necessary. One physician explained that he never consults with an ethics committee, although he does engage in ethics consultations:

"I'm happy to report that I've never actually used our ethics committee. We have one. I could. It's available to me. Instead I've used a lot of …the infrastructure at the hospital. We've actually got some really great social workers, and they've been very instrumental in educating families in those kinds of things. The [hospital] has actually been reasonably open with my associating with the Area Agency on Aging, so I can interface with other community programs to say maybe we can see about an advocate, maybe we can do those kinds of things."

The Impact of Diversity

The more successful ethics committees discussed by informants were reported to be fairly homogenous in terms of world views, notwithstanding some political differences. Several informants speculated on how well a more diverse ethics committee might function:

"[Name of hospital], which probably has a rather unitary view of ethics, may be functional or high functioning. If you get more diversity, how do you get consensus in that setting, and to what extent is that destructive of the effective functioning of an ethics committee? I'd be interested to know how that plays out in real life."

A colleague opined:

"I've not seen it [diversity] play out in a committee setting. Probably the closest I came to it was at Hospice of the Valley, which had pretty diverse backgrounds and opinions, but when it comes down to the rubber meeting the road with patient issues and clinical ethics, it would be tough to come to consensus if you have totally different world views."

Several informants stressed the importance of augmenting organizational support for ethics committees by bringing perspectives other than ethics alone:

"I'm glad to hear [name of hospital] has gone to the point of actually training the people that sit on bioethics committees. In our medical school, we'll actually be doing mock bioethics committee meetings and bring in attorneys and other perspectives and have the students start thinking a lot more, because the issues are going to get harder, not easier."

Dimensions
of Ethical Issues

Ethical issues addressed in the interviews and focus groups quickly moved beyond the dimensions of clinical ethics proper – patient care and well-being – to the hotly contested economic, social and political dimensions of the larger market-driven environment, where issues of social justice, human rights and dignity encompass more than medical treatment. Clinicians perceived their first responsibility to be the ethical care of patients, but they also were acutely aware of working in an increasingly industrialized environment where "doing the right thing" often took a back seat to "doing the required thing" as defined by the larger "system." This creates the conditions for moral distress (see box).

The following is a short summary of some of the more salient themes from these conversations, and illustrate the fault lines between moral dilemmas, moral distress, personal responsibility and the requirements of practicing medicine in so called "post-industrial" society.

Advance Directives

There was a diversity of views on the subject of advance directives, as well as confusion on what was legal and what was not, and whether families or clinicians could override a patient's expressed wishes through an advance directive. Terms like 'advance directive,' 'living will' and 'power of attorney' were often used interchangeably – some clinicians thought advance directives were extremely useful, while others thought patients often didn't have a clue as to what they "really" wanted at the end stage of life, and besides, they were often overturned anyway. Here are representative comments:

"Legally, that [advance directives] was one of the best things we've seen happen, to remind people that they have the right to make those decisions and at a time when they can make those decisions, they will make them. I think it was brilliant in a great many ways. I think it has ended up saving the system a lot of money, because people would not want to have some of the things done that are done. It's very reassuring to know what somebody really wants and to show them to a skeptical, grieving partner or family member. This is what he or she wanted when they were competent…I think they are working wonderfully."

Moral Distress

Part of the conversation among participants in the interviews and focus groups centered not on the resolution of ethical dilemmas – deciding what ought to be done in the face of competing values and principles – but on feelings of *moral distress*: being aware of a moral problem, knowing what ought to be done but, because of real or perceived constraints, not being able to act on it.

This was most evident when the discussion turned to practicing medicine in an industrial environment where principles of efficiency and cost effectiveness, legal and regulatory constraints, and the pressures of control and standardization conspire to prevent what many clinicians perceived to be the right way to practice medicine and act *ethically*. In the words of an ER physician:

> *"If I didn't have to feed my family or keep my medical license, I probably would go into someone's room and tell the family, look, this is absolutely ridiculous, you have to let them [the patient] go, pull the tube right now, and give them a long drawn out of here's why you are doing something wrong. And you can't do that, because you're going to spend hours sitting in front of your hospital board explaining why you told the family they are wrong."*

Distinguishing between moral dilemmas and moral distress is useful in "unpacking" ethically charged situations in health care, and is the proper purview of ethical consultations by persons trained to see what can be changed, and what cannot. But, as the interviews and focus group discussions so eloquently illustrated, clinicians lump these categories together in narratives of shared practice and culture that are considerably more complex and ethically tangled than any ethical schematic covered in a bioethics seminar might suggest.

Creating the organizational space in which to share these narratives is one of the important functions of an integrated bioethics educational program. Experiencing moral distress is a given. How one responds to it is not.

"These advance directives get abrogated in a crisis. I had one patient who, well, needed to die, had end stage lung disease, had been on a ventilator seven times, had a living will, just wanted comfort care, and he comes into the emergency room, and the physician just keeps working on him. They don't even look [for advance directives]."

"We've changed the definition of terms. We've changed just providing basic food and water into something that is a heroic medical intervention, and that people are signing these things without, perhaps, realizing exactly what they mean, and people should have a very clear idea of that document that they are signing."

"Sometimes people sign things, and they really don't understand, and then when the reality comes, they want to change what they've signed…Is it good or bad, I don't know, because I've got a number of families saying, well, she didn't really mean to sign that. She wouldn't have wanted this or that. She would want you to do 'C' instead of 'A.'"

Within this diversity of views, there was widespread consensus that both clinicians and patients needed better education and support when it came to advance directives, and that this was a proper role for both bioethics committees and for statewide policy initiatives and broad public education. Arizona legislation governing health care directives (A.R.S. Title 36, Ch. 32) was referenced as necessary and influential in that regard.

Privacy and Surveillance

Balancing patient privacy with the need to obtain information for patient monitoring and treatment was a subject of discussion, as was the balancing act between patient confidentiality and issues of safety. In Scenario #3, for example (page 21), where a 14-year old boy's disturbing drawings raised issues of his own and other's safety, clinicians unanimously favored erring on the side of safety compared to respecting the adolescent's right to privacy, even though most favored keeping the parole officer out of the picture and concentrating instead on open communication with the parents and psychiatrist:

"Talking about the parole officer. I'm with the rest of you [not bringing him into the picture], but communicating with the parents or the people who are responsible, communicating with the psychiatrist, ethically I think that would be extremely important."

In other situations, clinicians commented on how effective treatment may involve violating patient confidentiality, especially if family members are to be enlisted in providing effective care:

"Wanting to enlist the family in trying to help the patient get better, sometimes, again, you walk a fine line there with privacy issues, because as much as you want to bolster their [the patient's] support system, a lot of times that can create conflict because they don't want family nagging at them. It's different if the doctor is doing it."

The subject of what we can do with technology to monitor patient status and treatment– and how it can conflict with patient privacy – came up:

"We can create smart houses, and we can put a sensor on the stove so if mom leaves the stove on and walks away after x-number of minutes, it'll shut itself off. We can put sensors on the doors, so we know if mom got up this morning, because we know she opened the cupboard door or she opened the bathroom door. We can even put a sensor in the toilet so we know if mom is going to the bathroom so many times a day…So again, it's about privacy."

Although the subject of advances in biotechnology (genomic profiles) and the need to protect patient information and privacy was mentioned, it was not a focal point of discussion, which was primarily limited to everyday clinical concerns. Still, clinicians were well aware of the need for hospitals to address the confidentiality of sensitive medical information that can have personal consequences:

> "I would like to think that hospitals are just starting to address and put in place people to help the staff [sort through confidentiality issues], and it's not just the emergency staff. There's got to be other ethical decisions that may be happening…when it comes to patient information and privacy, and how are we protecting our patient. There are a lot of different ethical issues."

End-of-Life Issues

As we've already documented, ethical issues in end-of-life care and related issues such as palliative care, futility of treatment, euthanasia and right-to-die were central topics of discussion. There was general agreement that more emphasis needs to be placed on palliative care when it's clear that the patient is not going to recover or get better physically, and it was a source of moral distress to be pressured to provide treatment that clearly was futile in the face of family pressures and economic incentives. Some representative comments:

> "I work in an elderly community, with a lot of futile care going on. It's a struggle for us to deal with patients, families, a huge waste of resources, the wrong people being treated."

> "I know there has been some push for [state] laws that when care is deemed futile by the medical community, the family has to pay out-of-pocket or else that's it, and obviously that's never going to pass. But would I support something like that? Well, it sounds mean and cold, but yes, because we have millions of kids who aren't getting child care, and some of the money we spend on futile care could easily be spent on them."

> "A mentor made the statement years ago that in the future we'd move to rationing health care. I didn't believe him at the time, but now I see us going that way. The ethical issues of end-of-life have always been around, but today the financial aspects are huge. How do we keep the hospital open, avoid massive layoffs, and still do what's ethical, what's right?"

> "Life is fragile, life is precious. I'm not the one to make quality of life decisions for people, but I don't understand why we have nursing homes full of people in vegetative states, and when they get a fever or get sick, we're forced to take care of them in an intensive care unit, and then ship them back to where they came from. It's sad. You can hardly die in society without going through an intensive care unit many times. It's a very dehumanizing thing."

Futile Treatment is Not Futile

But not everyone agreed that futile treatment was "futile." An internist held to a firm belief that the physician's moral duty is to "do no harm," and that meant keeping people alive:

> "Futile care used to mean it didn't work. You tried it, and the patient died because it didn't work. Well [today], futile care, we don't do it because it might keep somebody alive."

Another participant interpreted "do no harm" differently:

> "We've had a few cases of medical futility. It's become a big issue. You know, when families say, 'Do everything,' and the doctor's saying, 'It's not medically appropriate for me, and I'm causing more harm…You have a woman with metastatic disease, basically dying, and the family's saying, 'You will resuscitate, you will maintain on a ventilator,' and the doctor's feeling, 'You know what? This goes against my values and my principles, and what I set out to do as a physician.' The first thing is to cause no harm. I think that plays itself out daily."

"Sometimes we cave into the family and prolong life when we know it's futile. I think we are allowing the family to induce suffering, and they have no respect for quality of life at that point. It also takes away respect for death."

The ethical dilemmas in pain management at end-of-life came up, and what some considered the fine line between making a dying patient comfortable and hastening death. A neurologist explained:

> *"If my [ALS] patient is dying fully conscious, suffering air hunger but not having pain, is my giving them narcotics, which is going to assuage that air hunger and let them go to sleep so they can die maybe a few hours earlier, is that doing harm or is that doing good? There are lots of gray areas out there."*

Cultural Diversity

The issue of cultural diversity arose within the context of being sensitive to the values and practices of different ethnic, religious and social groups, and not necessarily as the result of facing difficult ethical choices. Many participants related stories of having to adjust care and treatment to accommodate cultural practices and special requests; the challenges presented usually resulted from economic and institutional restraints, as well as from one's own perceived cultural biases. An ICU nurse gave this example:

> *"We had a 93-year-old patient who was Buddhist and a DNR [do not resuscitate]. The family said they wanted eight hours of uninterrupted time with nobody touching him to chant over his body. And of course we needed to get him out of the ICU because we didn't have a bed, so we worked on getting him a private room. Lots of times we don't always ask a family what they will need if the patient dies."*

One clinician recalled how upwards of 250 members of a "gypsy" clan convened en masse at the hospital to see a dying member, and how she ended up consulting with a medical group in Oregon that had experience with this particular group and knew how to handle the situation. Others recalled situations where care had to be taken when assigning medical personnel to particular patients:

> *"[You get] a patient who does not want to see a Muslim doctor. They're in the emergency room and [they think] it's the emergency room's job to find them a non-Muslim…Or we get this with Muslim women, they say they won't see a male physician, but I have had them all pretty much be willing if that was the only alternative. It's not our obligation to provide you with a certain gender of doctor – or a doctor with a gender that is acceptable to you – but the simplest or quickest thing to do is to say, okay, fine, we'll accommodate you."*

Other examples included being sensitive to the culture and traditions of Native Americans (including a tribal healer as part of the clinical team, wearing ceremonial garments) or dealing with devoutly religious people who refused to let their loved one die, even when nothing else can be done for them. Most of the participants agreed that knowledge of, and sensitivity to, different cultural traditions was a way to respect the autonomy of patients in their care, and therefore part of their ethical obligation.

System Issues

Moral distress from having to practice medicine in an inherently unfair, inefficient and occasionally ineffective health care system, where business interests and the financial bottom line often trump the principles of beneficence, nonmalificence and justice, surfaced repeatedly in these discussions.

Professionalism

A number of physicians stated categorically that the entire moral basis of the medical profession was under assault:

"Part of the milieu in medicine these days is more driven by income than in caring for the patient. And that has affected our sense of professionalism."

"When I was in medical school, I was trained in medical activism, committee work, ethics, that sort of thing. I don't know where it got lost, because I didn't lose it, but you seem to see less of it these days."

"It used to be that there was some margin in your day for time to follow your patients to the hospital and look in on them, or some margin in your income so you could provide some free care, or margin even in energy to do something more than just to survive. That margin is gone. It's down to, like, production."

Access, Cost and Responsibility

Clinicians were troubled by the high cost of health care, the mandate for hospitals to provide care when other institutions had no such mandate, large numbers of undocumented people and citizens without health insurance, and the increasing impersonal nature of the entire system:

"The other thing that comes to mind is the whole issue of treating undocumented patients. I hate to bring it down to deserving or undeserving, but as our health care resources get more and more stretched, where do we draw the line? It goes beyond just those without insurance…How many times do you see us doing dialysis on 85-year-old individuals, you know what I mean? It brings up socialized medicine and everything. There are ethical issues to it because I think that we, as a society, want to save everybody."

"We have a big problem in this state with hospitals bearing responsibility of the community when these people [undocumented, no insurance] get sick…Hospitals are the only facilities that are required to care for people. Home health agencies, nursing homes – none of them is legally required to provide care. The dilemma is not small. The issues around immigrants affect everybody. It's not just a matter of border security. When we get people for care, or inherit people for care from other facilities, we have to take care of them. That's an ethical issue."

"There is a distancing in health care. Some people are asked to screen, and they don't have to withhold care, they just have to say, 'No, we can't help you', but they don't have to actually see them necessarily. It protects me as a physician because I would have a hard time looking at someone and saying 'I won't help you.' I could – I can physically do it – but I can't do it according to the rules of the system in which I work."

"So much of what we see at the level of the bioethics committee is issues that arise because of strangers taking care of strangers…so now the physician is fungible, and the patient is fungible. The patient is now an object, not a subject. The patient is not a person, and the doctor isn't a person, and this is wrong-headed."

A physician commented on the ethical tug between public health and individual benefit:

"You might be able to immunize thousands of kids for the extra money you spend to fly one child out of state for some type of special treatment, versus treating him closer to home. That's public health versus individual medicine. Those are tough decisions."

"The American Medical Association was built on two pillars, medical education and ethics. That's what fostered professionalism at the beginning, and we have drifted away from that, due to economics and other things."

Another participant zeroed in on the moral issues inherent in an imported workforce:

"We don't train enough physicians and nurses to meet the needs of Americans, so we import them. We steal the best and brightest from countries that need those physicians and nurses because we're not addressing that issue. That's kind of an interesting international ethical issue."

A hospital administrator gave an example of ethical issues in health care management:

"There are ethical issues in how I make decisions. Do I make it only on financial criteria? For example, there are some places that will not take certain types of patients, mainly procedural kinds of things, because they are too expensive. Some of the spine surgery is really expensive, and we don't make any money on those; in fact, we lose money. So, it's my decision to not allow spine surgery, or even worse, to not allow certain spine surgeons to be on our staff because of what I call 'economic credentialing.' I see that as an ethics question in health care management."

System Fragmentation

Moral distress from the fragmentation in the delivery of effective patient care – a perennial topic in past SLHI reports – came up repeatedly:

"One of the ethical issues I see is fragmentation of care. Even within the same hospital, you get one hospitalist one day, another one the next. The same with nurses. There's no continuity like we used to have."

"The ethical issue I see is lack of access to follow-up. We have patients go through express care in the emergency department, and we tell them to go to primary care, and that's like sending them down some black hole. It's just not there. It's not an ethical environment."

"Fragmentation is systematic. I send patients to the specialist; the specialist doesn't tell them what is going on. They have to see me to know what happened at the specialist, but the specialist doesn't always tell me. It's unethical not to communicate what's going on."

"All of this fragmentation is being driven [by] the declining reimbursement for physicians. They've had to become more efficient and more productive. And going back and forth between the office and hospital is very inefficient. So in order to make ends meet, they have to see more patients…It hasn't worked, really, to bring down overall spending or costs or anything, but it's driving physicians to behave differently. Doctors who used to go to hospitals have stopped."

"…At that point [in the fragmented care process], the critical care specialist abrogates everything else that everybody has decided…this other physician decides, I'm not paying any attention to any [previous treatment information]…we're going to do everything, everything, everything, everything, and finally the bioethics committee has to come in and unravel that whole process."

Technological Change and Challenges

The ability to do more with technology to both enhance and prolong life was a recurring theme. What once was scarce is now commonplace; what once was an exception and privilege is now viewed as a right. Dialysis – once the purview of "God Committees" – is an example:

"I remember when I was a student or an intern, I forget, I had to present a patient to the ethics committee who was a candidate for dialysis, and I had to make the case that he was a solid citizen and had the potential to recover and return to work. And that of course was ancient times. But now we do too much. Recently a nephrologist told me a joke of why they put nails in coffins, so you won't keep taking them in for dialysis."

Clinicians felt the moral distress from doing something simply because it was possible, and not because it was desirable or beneficial:

"The whole world has changed in terms of what's possible…what's possible does not necessarily mean what's best for a specific patient, and yet physicians are often under a great deal of pressure that they put on themselves and the families put on them to use technology if it's available."

Increasingly, death itself is viewed as a failure:

"I also think that physicians see any outcome in death as a failure, and so if we, ourselves, can't even face mortality, then how are we going to struggle with our patients going through the same situation?"

Technology and Infants

While the media tout the latest "miracle birth," clinicians in the interviews and focus groups spoke eloquently about the moral dilemmas in keeping pre-term, low birth weight babies alive indefinitely, or infants born with massive physical problems that would have resulted in their death decades ago when life enhancing technology wasn't available:

"The absolute biggest [ethical challenge] today is the extremely low birth weight baby, those right at the margin of viability, and for better or for worse, society doesn't easily defend us [clinicians] from not doing things…Society much prefers to be critical of withholding care. So since society doesn't support you for not doing the care, and in ambivalence, you do the care, even though you may not agree with what you are doing, because the reality is, the public is clueless."

"The ethical dilemmas that go along with dying are part of normal existence on this earth, and there is a limit both to what you do and how much you can do for patients. And disability is equally a part of normalness, and it's so escalated out of control in this country for everybody expecting everything, and for it all to be paid for by somebody else. These are big, big issues."

One neonatologist gave this artful explanation of how he employed the same technology used to keep infants alive to educate patients about medical futility:

"We all know what babies are supposed to do. They are supposed to move. They are supposed to blink. They are supposed to look around. It's nice if they breathe, but we have them on breathing machines for their lungs. But when the parents consistently see that the baby does not move, the baby does not breathe, and you go over there, and you flip the ventilator off, and they are watching to see if their child breathes, okay? And I'm watching to see if their child breathes, and that child doesn't breathe, so we turn the ventilator back on. They get the message."

"I see children with hosts of congenital anomalies, and people would be just appalled if they weren't treated here… America has kind of gotten to where death is a bad thing. Okay, it is a bad thing. The reality is, sometimes the treatment is worse. We have to put that into loving perspective."

Technology and Distancing

Other medical technological applications have ethical implications. A few participants commented on the growth of telemedicine and the use of electronic media, primarily the Internet, for transmitting medical information, advice, and even diagnoses and treatment. A psychiatrist/internist in private practice explained how telemedicine and the Internet can be used to make "house calls" and provide other services:

> *"We're setting up a telemedicine system right now in my house where I'm now going to be meeting with patients all over the state through high-speed videoconferencing. So it's another layer of potential distance between us that I think also becomes somewhat of an ethical problem because, you know, the traditional model of face-to-face health care that we've always coveted so much, the question is how is that going to change the way we treat patients, and are we going to favor that [distance medicine] over face-to-face medicine and possibly continue to lose more and more touch and intimacy."*

distance medicine vs. face-to-face medicine?

Balancing Act:
An Arizona Agenda

The Ethics Iceberg

After documenting a wide range of ethical issues in medicine that have arisen over the past 50 years, it may come as a surprise to hear that we believe this is only the tip of a vast ethics iceberg, the greater portion of which remains below the surface, hidden from view by traditional notions of professional roles and practice, a language of individual consumerism, autonomy and free market inviolability, and a naïve, if comforting, faith in science and good intentions to save us.

A global ethics warming is underway. The iceberg is slowly melting and threatening to flood us all with stark choices of resource allocation and purpose: who gets what, why they get it and – most importantly – *who decides*.

Arizona physicians, nurses, social workers, clergy and managers who participated in this study were acutely aware of the ethical dilemmas in medicine and the moral distress of trying to do the right thing within an increasingly industrialized system of care where, as a number of informants commented, subjects become objects, care becomes modes of pro-duction, and "strangers end up taking care of strangers." They spoke about their challenges in dealing with value-laden decisions related to patient autonomy, family conflict, privacy, technology, futility of treatment, the right to live or die, advance directives, competency and surrogate decision making, withdrawing or withholding treatment, and other issues in clinical practice. But – and this is what we didn't fully anticipate – they provided compelling and often emotional testimony about making those decisions within a complex and even perverse bureaucratic system that, by its very nature, induces ethical anxiety and stress.

Time and time again, they said they knew what they *ought* to do, but felt that they couldn't always *do* it – the very definition of moral distress.

One agenda to enhance ethical awareness and decision making in Arizona health care.

Empowerment

But moral distress has an upside. It can lead to *empowerment*. It can lead to positive change and growth, both in individuals and social systems. The hospice movement, which grew out of the moral distress of industrialized approaches to end-of-life care, is an example. Inform-ants repeatedly mentioned hospice as a model of ethical care – the integration of mind, body and spirit within a responsive, caring atmosphere. Ironically, one has to be dying in order to receive it. Why couldn't the entire health care system adopt a more hospice-like approach? Why couldn't hospitals, for example, adopt the values of *hospitality* and create a culture of ethical caring? More to the point of having to operate within a culture of health care consumerism that conflates individual autonomy with the right to demand unlimited serv-ices, why couldn't the entire health care system be empowered, as one Arizona physician suggested, "to offer only what's appropriate?"
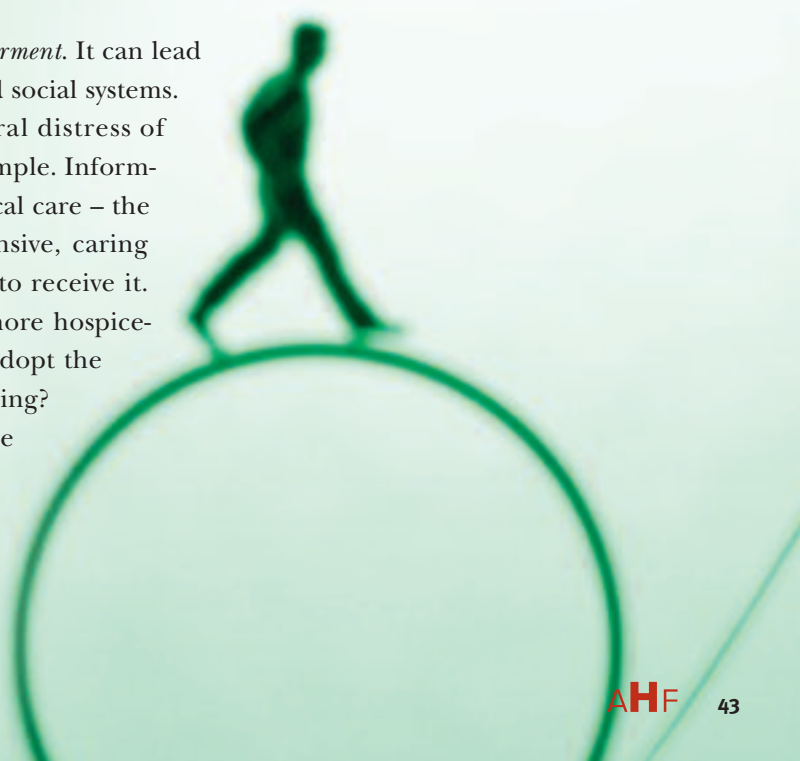
IntegratedEthics

As the largest health care system in the U.S. and a recognized leader in healthcare quality efforts and the use of health information technology, the Veteran's Administration (VA) has embarked on *IntegratedEthics*, a national educational and organizational change initiative from VA's National Center for Ethics in Health Care.

The goal is to make ethics education and consultation more integrated, systematic and comprehensive across the VA system. Tools that create efficiencies of scale – policies, manuals, guidance on ethics consultation and how to handle difficult situations at the system level – will be developed to alleviate the pressures on individual facilities to solve problems in isolation. Instead of being primarily *reactive* – dealing with questions about end-of-life care on a piecemeal basis as they come up – VA ethics committees will be networked to become more *proactive*, "ready to address a broad set of issues across a lifespan, and to do it with increasing resource constraints."[29] Not only will efforts be focused on decisions and actions as the result of clinical ethics consultations, but they will also focus on processes at the system level (preventive ethics) and on ethical leadership at the larger environmental and culture level.

Initiated in 2007, *IntegratedEthics* is perhaps the largest effort to standardize and measure the work of ethics consultants in the U.S. By September 2008, officials say the VA will be electronically recording all ethics consultations and outcomes. Almost 20 years after the Joint Commission mandate to create ethics committees, the VA has decided to create "standards for quality" in ethics consultation, and to "prove their value on the ground."

The *IntegratedEthics* website (www.ethics.va.gov/IntegratedEthics) contains a number of training and reference tools that are helpful to anyone interested in addressing ethical issues in healthcare settings.

In social systems, empowerment is a function of education, skill development and leadership, as well as access to the human and material resources necessary to advance a common life. The *Balancing Act* surveys, interviews and focus groups all underscored the importance of education and training in recognizing, articulating and addressing ethical issues in medicine, but they also illustrated that without access to resources or an organizational culture that supports ethical practice, that education may lead to even more frustration and high levels of moral distress. Recent national research that documents high burnout rates among nurses and social workers confirms this.[28]

Education is a necessary, but not a sufficient, condition for empowerment. We need more than ethics committees and ethics education. We also need to work together to advance a political and social agenda that fosters an environment and culture in which an ethical health care system can flourish.

The following is one agenda to enhance ethical awareness and decision making in Arizona health care, and to address the broader system and cultural issues that can cause moral distress.

1. Increase Visibility, Expertise and Support for Systematic Ethics Consultation

The surveys and interviews documented wide variation among Arizona hospital ethics committees in providing ongoing consultation services at the bedside, ranging from a few larger, well established services with trained bioethicists and strong institutional support to committees that function in name only and have little integration with daily clinical care. In the case of Arizona long-term care facilities, the situation is especially bleak, with 50% of survey respondents reporting having no access at all to ethics consultation services, and

almost 40% who "weren't sure." However one slices it, there is clearly room for improvement in providing clinical ethics consultation services in Arizona healthcare facilities.

There are good role models in Arizona for others to follow. Informants mentioned St. Joseph's Hospital and Medical Center and the University of Arizona Medical Center as two institutions with strong ethics consultation services. There are also good local sources of training in bioethics for clinicians and other healthcare professionals – Midwestern University in Glendale offers instruction in bioethics and medical ethics, as do the University of Arizona and Arizona State University.

In addition to learning from knowledgeable peers and taking advantage of educational resources in the community, here are some strategies to consider at the individual and institutional levels:

◎ **IDENTIFY AND SUPPORT BIOETHICS LEADERSHIP.** Every institution has individuals who can provide strong leadership in promoting and implementing ethics consultation services. Too often, these leaders are asked to "start" programs with little organizational support and encouragement. Instead, leaders throughout the organization must come to understand the scope and role of ethics consultation, get into the habit of seeking advice from the ethics consultation service when appropriate, encourage others in the organization to utilize these services, and recognize staff for their ethics consultation activities. The goal is to make bioethics leadership an underlying value and goal of the entire organizational enterprise and culture, and not isolate it within any specific committee.

◎ **INTEGRATE ETHICS CONSULTATION WITH OTHER PARTS OF THE ORGANIZATION.** Instead of limiting the functions of the ethics committee to individual clinical cases, membership might be expanded to include leaders from other areas of the organization where ethical issues arise (patient advocate programs, legal, research, compliance, human resources, etc.), which in turn can lead to the deeper goal of creating an ethical work environment and culture. Taking a page from the VA's playbook, the clinical consultation services might be part of a larger ethics "council" that reaches across the entire organization. Fundamentally, ethics consultation at all levels is a core component of institutional quality, and thus needs to be integrated across the system.

◎ **INCREASE EXPERTISE IN ETHICS CONSULTATION.** All institutions should have at least some people trained in the techniques of ethics consultation. Indeed, one of the critical functions of ethics committees is talking about ethical issues in medicine with all staff and providing opportunities for further education and training. The surveys clearly show that this is an area of weakness for many ethics committees in Arizona. It is ideal to have trained bioethicists on staff and readily available, but there are plenty of ways to expose all staff to learning how to recognize and approach ethical dilemmas. This includes not only training in ethical reasoning, but training in communication, mediation and group dynamics. Education and training in ethics consultation should be a priority for all Arizona hospitals and long-term care facilities. Simply implementing a regular ethics newsletter or other institution communication vehicle is a start.

◎ **ENSURE STAFF TIME FOR ACCESS AND ACCOUNTABILITY.** Ethics consultation, done correctly, is not an optional or voluntary activity, but should be an assigned role with dedicated time and resources devoted to it, as well as having a clear path of accountability for results. As the summarized research illustrates, lack of time

Ethics consultation at all levels is a core component of institutional quality, and thus needs to be integrated across the system.

and the press of daily events often result in not addressing ethical issues in a systematic way. It's about more than having ethics consultation services available in inpatient clinical settings; ethical issues are also found in outpatient, long-term care, home care and other settings. In addition to having sufficient time and support resources for ethics consultation, there should be specific goals, structures, processes and performance expectations in place to document that consults actually are worth the time they take. Someone has to be responsible – and accountable – for results.

◎ **DEVELOP, APPLY AND EVALUATE ETHICS POLICIES AND PROCEDURES.** As the University of Arizona's Dr. Iserson recommended earlier (page 30), the health care organization needs to have proactive ethics policies and procedures in place that spell out the who, what, why and how in specific situations and, in effect, mandate the requisite behavior. The more broadly these policies and procedures are developed consensually in the workplace, and the more clear and specific their application to the types of ethical issues documented in this report, the greater their acceptance and application by the appropriate staff. Like other areas of the organization, ethics policies and procedures should establish "best practice" standards of ethics consultation, against which actual practice in the organization can be evaluated.

2. Resurrect and Expand the Arizona Bioethics Network

In the late 1980s-early 1990s, several Arizona leaders and groups came together to create the *Arizona Bioethics Network (ABN),* an informal "adhocracy" to support burgeoning hospital ethics committees and provide education and training for clinicians, policy leaders and others on ethics issues in medicine. The ABN sponsored a number of conferences and workshops, and generally enjoyed a healthy level of member participation and institutional support, but without any type of formal structure, base financial support and leadership specifically focused on its future, it quietly faded away after a number of years into what its former volunteer director characterized as "organizational dormancy."

We believe the timing may be propitious to resurrect and expand the Arizona Bioethics Network. With a small but growing core group of bioethicists and bioethics programs in Arizona, an expanding health care industry, and ever more contentious ethical issues of resource allocation and cost-benefit, there is a clear need to collaborate across institutional settings and professional roles and create a true *learning network* to develop and support an ethics healthcare agenda in the state.

There are two keys. One is *leadership.* Nothing of any significance will be achieved without a small group of core leaders who are respected by their peers and are committed to doing whatever it takes to make the ABN a valuable part of the Arizona health care landscape.

The other key is *collaboration*: Clinicians, bioethicists, clergy, social workers, lawyers, researchers, hospitals, long-term care/nursing facilities, hospice, education programs, consumer representatives and policy leaders all need to come together to set out and implement a common agenda:

- Serve as an independent, nonpartisan forum for the promulgation and exchange of knowledge and best practices in Arizona bioethics issues.

- Support education and training in bioethics across the entire health care spectrum. In addition to ethics consultation services, this might include organizational and system-wide issues mentioned frequently by study participants as a source of moral distress.

There are two keys.

One is leadership.

The other is collaboration.

- Develop both virtual and real-time ethics tools – best practice policies and procedures, case studies, workshops/seminars/conferences/webinars, links to established educational programs, consulting services, etc.

- Conduct and/or oversee research to inform ethical decision making and consultation at multiple levels.

- Review, analyze and recommend policies and legislation to improve ethical decision making at the individual, organizational and state levels.

- Engage in and support public education and advocacy on ethics issues in Arizona health care.

- Serve as the voice of bioethics education in Arizona.

Based on SLHI's experience in facilitating other learning networks and communities of practice, the ABN will need:

- Staff specifically focused on its mission and activities. Having to rely solely on the good intentions of volunteers, no matter how skilled or committed, probably won't get it done.

- Some type of formal organizational home and/or support. Possibilities might include the Arizona Medical Association, the Arizona Hospital and Healthcare Association, an institution-based bioethics program or some other organization/combination thereof. The ABN itself can remain unincorporated, but it still needs strong organizational affiliation.

- Base financial support. Grant money could get this started, but some type of dues/membership structure, as well as income-generating activities, needs to be articulated. A business case and plan would need to be developed in any case.

3. Improve Education and Understanding of Palliative Care

The issue of palliative care generally, and hospice specifically, came up frequently enough in the interviews and focus groups that it is listed as an area of recommendation in its own right. One might expect to hear this from nurses and people in hospice, but we heard it from a number of physicians – specialists and generalists alike -- as well.

Many participants in this study agreed that some of the ethical distress they encountered resulted from continuing to provide medical treatment of dubious or no value instead of utilizing palliative care earlier in the end-of-life process. They recognized the need to educate more palliative care specialists, but they also called for more palliative care education for *all* staff, and especially for physicians who are accustomed to treating people with a technical bag of tricks, even when that treatment is generally recognized to be futile.

Participants considered hospice to be an example of integrated, compassionate and holistic care, and recommended that patients should be referred to hospice earlier in the end-stage process. Additionally, some participants gave examples of providing palliative care in the hospital as a way of improving patient quality of life and actually reducing hospital costs for expensive end-of-life treatment at the same time. A further examination of palliative care is outside the scope of this report, but it's important to note that the palliative care train has already left the station in many hospitals and long-term care facilities across the country, and there is a growing education and advocacy movement for palliative care both within healthcare institutions and in the general public.

The Arizona Bioethics Network was a good idea 20 years ago. It's an even better idea today.

Finally, there is a clear need for better education with regard to pain management as part of palliative care, especially in situations where there is a fine line between adequate pain control, abuse of narcotics and/or hastening the patient's death. The ethical and legal issues in pain management alone are sufficient reasons for better education in palliative care.

Palliative care education and advocacy might well be an issue for the reconstituted Arizona Bioethics Network to take on.

4. Consider Legislation to Address Futility-of-Treatment Issues

Participants noted many cases of disagreements with family members and surrogates on prolonging life in situations where further medical treatment was deemed to be clinically futile, and it was in the "best interest" of the patient to provide palliative care only and let "nature take its course." These conflicts arose even in cases where patients with advance directives had made their wishes clearly known.

Futility of treatment is hardly a new issue in medicine – Hippocrates himself noted that it is the "master physician" who learns the signs and "refus[es] to treat those [patients] over-mastered by their illness"[30] – but the advent of life sustaining technology and drug therapies gives frail and dwindling patients ever more treatment options that may impact quality of life. In the words of Dr. Bruce D. White, a principal contributor to this report, "for patients, surrogates and health care team members, there will be new dilemmas to resolve as the efforts to balance beneficence, nonmaleficence, autonomy, and justice mature while we move forward with providing for those who are in desperate straits at their end-of-life."[31]

Dr. White and others believe it may be time to consider legislation that addresses futility of treatment conflicts in Arizona, and cites Tennessee and Texas as two states that have such laws in effect. In Tennessee, for example, it is lawful for a health care provider or institution to "decline to comply with an individual instruction or health care decision that requires medically inappropriate health care or health care contrary to generally accepted health care standards applicable to the health care provider or institution," provided that "all reasonable efforts to assist in the transfer of the patient to another health care provider or institution that is willing to comply with the instruction or decision" have been made.[32]

Without such legislation or other type of statewide regulatory guidance that puts a "process check" on patient autonomy, Arizona clinicians, ethics committees and health care organizations are left to resolve medical futility or inappropriate medical treatment conflicts on an ad hoc, piecemeal basis. While the area of medical futility is complex and contentious, it seems a reasonable course of action to evaluate the experience of other states in addressing it, and determine whether it makes sense to craft similar legislation in Arizona. This, too, could fall under the purview of the Arizona Bioethics Network.

5. Improve Cultural Competency

The provision of "culturally competent" medical care has long been advocated as a key strategy for reducing or eliminating racial and ethnic health disparities. It is especially important in dealing with the types of ethical issues discussed here, where patients and their families from various ethnic, cultural or religious backgrounds may hold a different set of expectations, customs and preferences than the caregiver. When these are not identified and dealt with beforehand, anger and distrust can result.

Strong religious feelings about the sanctity of life, for example, can make it difficult to talk to families about futility of treatment and prepare for the patient's death. A culturally competent medical team, including clergy, will be able to identify these issues in advance and, through patient/family-centered communication, move toward resolution of any disagreements with shared decision making and respect for patient and family preferences.

While the area of medical futility is complex and contentious, it seems a reasonable course of action to evaluate the experience of other states in addressing it, and determine whether it makes sense to craft similar legislation in Arizona.

Some of the clinicians and ethics team members who participated in this study said they learned about the importance of cultural competency the hard way: not being sensitive to the values, beliefs and cultural preferences of the patient and family, and creating a climate of suspicion and distrust as a result. They stressed that all health care professionals, regardless of their role in patient care, needed to be well versed in perspectives from different racial, ethnic and religious backgrounds, and that this was a function of ongoing training and education.

Hospital and long-term care ethics committees should make cultural competence part of their educational mission with all staff, and with the clinical care team in particular. Some of them already do this, but based on feedback from this study, others do not. This has to change. Material addressing different racial, ethnic and religious expectations and preferences regarding end-of-life, privacy, authority, autonomy and other potentially ethically charged issues should be readily available and disseminated as widely as possible in the health care setting. An online source – another potential project for the Arizona Bioethics Network – is another possibility.

## 6. Balance Autonomy with the Ethics of Responsibility

Perhaps the most surprising result of these conversations with Arizona caregivers about ethical issues in medicine was the sheer amount of frustration, anger and even sadness expressed about the state of health care today in the U.S. This was directed not only at the health care system itself – fragmented care, bureaucracy, inefficiency, ineffectiveness, the dominance of "production over people" – but at patients, families and the larger American consumer-driven culture, where we are accustomed to "having it our way" all the time, whether it's in a hospital or a restaurant.

To paraphrase one of the key "take-away" points of these discussions, we need to balance the ethics of individual autonomy and rights with an ethics of *social responsibility*. There are, in fact, no completely autonomous, self-determining individuals. The self is a social construct: we are all unavoidably connected to each other, and to the greater natural and social environment that sustains us. The freedom of choice to request dialysis for a 90-year-old patient with advanced end-stage disease has to be balanced with a cost-benefit analysis that takes into account a socially responsible justification of resource allocation. The principle of respect for autonomy has to be balanced by the principle of justice, or fairness, as well as a principle of beneficence that is socially as well as individually grounded. Like it or not, we are in the world *together*, and it is together that we build the *trust* necessary to exercise our freedom of choice *responsibly*.

The ethics of responsibility – the ethics of *social ecology* – are at the heart of the health care reform debate in the U.S. The time has long since passed for physicians, nurses and others in the health care system to passively accept the status quo. Like all of us, they, too, must be in the vanguard for health care reform. They, too, must provide the leadership and moral courage to create a caring, humanistic environment in which ethical principles can be effectively translated into ethical practice. They, too, must put ethical behavior at the core of a responsive – and responsible – life.

Self and others, others and self. That is biggest balancing act of them all.

There was a significant amount of frustration, anger and even sadness expressed about the state of health care today in the U.S.
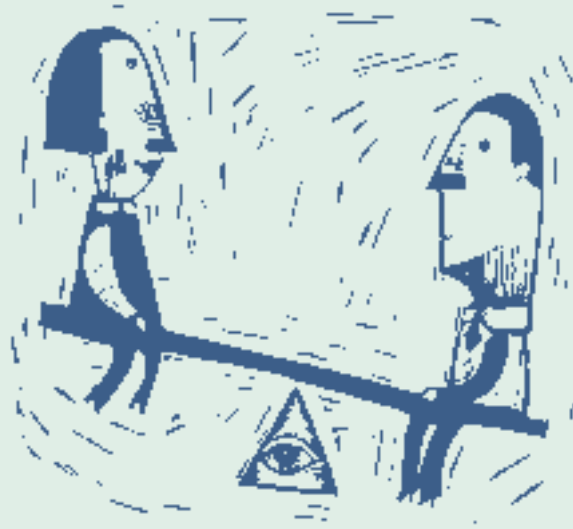
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Man always travels along precipices.
His truest obligation is
to keep his balance.

Pope John Paul II (1920 - 2005)

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Our Mission

To improve the health of people and their communities in Arizona, with an emphasis on helping people in need and building the capacity of communities to help themselves.

The purpose of *Arizona Health Futures* is to unravel an important health policy topic of relevance to Arizonans, provide a general summary of the critical issues, background information and different perspectives on approaches to the topic, tap into the expertise of informed citizens, and suggest strategies for action.

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