

A Design for Change

ISSUE NO. 4

CRITICAL ISSUES IN CARE FOR CHRONICALLY AND TERMINALLY ILL KANSANS

SECTION I



L to R: Dr. Bob Twillman, University of Kansas Hospital, Meredith Mauck, Harry Hynes Memorial Hospice, Rep. Delia Garcia, Rep. Geraldine Flaherty and Rep. Nancy Kirk discuss end-of-life issues at the September 29, 2005, public policy forum held in Topeka.

Pain Management: Promising Practices and Frightening Fragmentation

The Problem

Pain is a major public health issue in our country and in our state.

- Chronic pain affects 35-50% of adult Americans (50-70 million people).¹
- 80% of patients seek healthcare because of pain.²
- Over 30% of acute care patients report poor pain control.³
- 50% of dying patients report moderate to severe pain.⁴
- Unrelieved pain costs our economy over \$100 billion each year.⁵
- 86% of dying cancer patients in Kansas experienced moderate to excruciating pain during the last months of life.⁶

“No patient should ever wish for death due to a physician’s reluctance to use adequate amounts of effective opioids.”

—Jerome H. Jaffe, MD

The Barriers and Concerns

There are few *actual* barriers to receiving good pain management in Kansas: No major provisions in any state statute, regulation or guideline significantly interfere with good pain management; disciplinary actions are relatively few; and interest is high for continuing education. There remain, however, numerous *perceived* barriers to treatment of pain in our state, from both the patient’s and the healthcare provider’s perspective, including:

- Healthcare professionals in our state often have not received focused training. They also lack knowledge needed

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to adequately manage their patients' pain. Many medical and nursing school curricula do not include adequate coverage of pain management.

- Many physicians fear the opinions of their peers, significantly impeding good pain management.
- Many physicians fear that the state licensing board or other regulatory or law enforcement agencies will investigate and sanction them.
- Patients fail to take medications as prescribed because of unwanted side effects, costs of medications or fear of addiction.
- Patients have difficulty finding physicians who will treat their pain adequately, especially in rural areas of the state.
- Patients have experienced problems with pharmacies filling prescriptions for pain medications.

- Patients have encountered obstacles with insurance companies and Medicaid paying for medications.

- Patients' expectations are low and they rarely serve as their own advocates.

- Physicians, patients and their families continue to harbor unrealistic fears of addiction and misconceptions about opioid analgesics and their physiologic effects.

- Costs of medications are a serious concern for many Kansans.

The Progress

Over the past five years Kansas has made great strides in implementation of adequate public policies regarding pain management and has been awarded high marks for our efforts by the Pain & Policy Studies Group at the University of Wisconsin.⁸

Clearing up the Misconceptions about Physical Dependence, Tolerance and Addiction:

Three distinct terms - physical dependence, tolerance and addiction - have been used interchangeably by the public, healthcare professionals, scientists and regulators for years. These misconceptions have also had the negative outcome of leaving patients with severe under-treated pain, because they (or their healthcare provider) fear that opioids will cause addiction.

Key Definitions:⁷

Physical Dependence: "A physiologic state of neuro-adaptation, which is characterized by the emergence of a withdrawal syndrome if drug use is stopped or decreased abruptly." Physical dependence is an expected result of opioid use, and physical dependence, by itself, does not equate with addiction.

Tolerance: "A physiologic state resulting from regular use of a drug in which an increased dosage is needed to produce the same effect, or a reduced effect is observed with a constant dose." Tolerance may or may not be evident during opioid treatment and does not equate with addiction.

Addiction: "A neurobehavioral syndrome, with genetic and environmental influences, that results in psychological dependence on the use of substances for their psychic effects characterized by compulsive use despite harm."

Kansas state licensing boards have been proactive in adopting policies and guidelines for the treatment of pain, including the *Joint Policy Statement of the Boards of Healing Arts, Nursing and Pharmacy on the Use of Controlled Substances for the Treatment of Pain*. This landmark state policy, the first of its kind in the nation to address all types of pain – chronic, acute and end of life – was adopted in 2002.⁹ The policy reflects the depth of commitment and desire that Kansas licensing boards have to supporting, encouraging and expecting quality and excellence in the assessment and management of pain. The Kansas State Boards of Healing Arts and Nursing also adopted similar guidelines for their licensees.^{10, 11}

The Recommendations

I. Improve Pain Management Education

Mandated pain management education may not be the solution, as the impact of this approach has not yet been fully evaluated. Initiating “half-steps,” such as specifically asking renewing practitioners to indicate hours of content in the area of pain management, might be a more acceptable approach.

We are making progress in medical/nursing school curricula offerings, but we need to continue working with faculty and administrators to improve content.

II. Change and Revise Policies

Address policy language related to the Principle of Double Effect¹¹, wherever it is found. This principle unintentionally reinforces the notion that opioids kill people. Its reference is not necessary for enforcement of state statutes, and

its elimination would not change the standard by which practitioners are judged.

Clean up language in the Medical Practice Act, which says that “excessive” prescribing is grounds for disciplinary action. “Excessive” is very hard to define. An alternative is to refer to the standards set forth in the Controlled Substances Act.

Open a dialogue with the Kansas County and District Attorneys Association and continue a dialogue with the Kansas Attorney General regarding the process to be undertaken when deciding on charges against a practitioner. Establishing a standard process would give reassurance to practitioners that someone who has sufficient knowledge and experience will judge them.

Exercise great caution in considering adoption of prescription monitoring programs, whose intent is to prevent diversion and abuse. There are database programs now in place, in approximately half the states, that track either Schedule II medications only, or Schedule II, III and IV medications. These databases can be used to identify patients engaging in suspect behavior and prescribers whose practices are questionable.

Congress passed the National All Schedules Prescription Electronic Reporting Act of 2005 earlier this year, which provides grants to states to establish and maintain these programs.

Kansas should exercise great caution in considering the implementation of a prescription monitoring program. Outcomes are hard to track, and one intervention is not appropriate everywhere. One unintended consequence may be restricted access for pain patients due to a chilling effect. Much analysis remains to be done, and other critical issues to consider

“A person’s report of pain is the optimal standard upon which all pain management interventions are based.”

—Joint Policy Statement

include:

- Who has access to data?
- How timely is access to data?
- Is the program administered by health authorities or law enforcement?
 - What requirements must be met for law enforcement to access data?
 - Is there an advisory group of practitioners to oversee the program and evaluate outcomes?

Assure that Medicare and Medicaid beneficiaries have access to pain medications. Access to pain medications, including opioid analgesics, needs to be as complete and unrestricted as possible for beneficiaries of these programs. Restrictions imposed on pain management drugs provided by Medicare and Medicaid could produce adverse outcomes for patients and the state. Further, restricted access could impair pain management and result in greater costs from other parts of these programs.

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⁷ All taken from Joint Policy Statement of the Boards of Healing Arts, Nursing and Pharmacy on the Use of Controlled Substances for the Treatment of Pain (2002). Found at www.ksbha.org/misc/jointpainmgmt.html.

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Left: State leaders participate in a public policy forum sponsored by the Kansas LIFE Project on September 29 at the Capitol Plaza Hotel in Topeka to learn more about issues related to pain management, advance care planning and artificial nutrition and hydration.

Right: Kathy Greenlee, Kansas Long-Term Care Ombudsman, addresses the panel, consisting of (L to R) Donna Bales, President/CEO of the Kansas LIFE Project, Representatives Bob Bethel and Nancy Kirk, and John Carney, Vice President on Aging and End of Life at the Center for Practical Bioethics.

Advance Care Planning: Processes and Documents

Advance care planning generally deals with three types of end-of-life decision-making processes and documents. Kansas has statutes governing all three types of decision-making.

The first type, known commonly as the *living will*, describes what type of care an individual seeks or expects at the end of life. Usually in writing, the living will takes effect when two physicians agree that the person is terminally ill.

The second document, the *durable power of attorney for health care*, names a surrogate or agent to make healthcare decisions for an individual when, and only when, the individual is unable to do so.

The third advance care planning tool, or advance directive, is a *Do Not Resuscitate order* (DNR). This document is signed by a patient's physician and directs the type of emergency care that an individual receives at the end of life. This order may be issued either in medical settings or outside of them.

Advance care planning documents serve a number of noble and necessary purposes.¹ They:

- Seek to preserve self-determination.
- Express and give effect to end-of-life preferences.
- Offer protection from maltreatment.
- Relieve anxiety and facilitate patient choice.
- Help loved ones when they must make treatment decisions.
- Protect financial resources.
- Decrease the risk of litigation.
- Can foster necessary communication.

Since the introduction and legal sanction of advance care planning documents in the US more than 30 years ago, evidence for their merits has grown steadily.

Although only limited studies exist, data support the contention that those with advance directives, when professional caregivers know and honor them, can lead to fewer deaths in the hospital, fewer intensive care days, fewer end-of-life resources expended, and increased family satisfaction.^{2,3}

Unfortunately, despite more than three decades of work, most Americans do not utilize these protections.

The Problem

- Of the 2.5 million people who die each year in the US, only about one-half million actually have written advance directives. Without the important conversations and/or document, family and professional caregivers are left in uncertain territory when attempting to honor a patient's dying wishes.⁴ In Kansas, it is estimated that fewer than 1/3 of all Kansans have advance directives.

- Eighty percent of those who die in hospitals are without the capacity to make decisions and many of these are on life-support.⁵

- A growing number of frail elderly do not have capacity to make decisions at the end of life. The US is an aging society and growing older. Dementia affects half of persons over the age of 85. Proportionately, that population is the fastest growing segment in society.⁶

- How we die is changing. Rather than dying from fatal episodes of acute illness and traumatic attacks, more people live for extended periods of slowly declining health. In 2004, for the first time,

Advance Directives Weaknesses:

Living Will Weaknesses

- As a rule, people don't do them or can't find them when they are needed.
- Too often, living wills are viewed by the patient/family as static and not as a process changing over time.
 - The document cannot anticipate complex circumstances and is often too vague to be meaningful.
 - The living will is often a complicated process defined by statute.
 - Formats and legal language vary state by state.
 - Many people confuse the living will with a durable power of attorney for health care decisions.
 - The living will is only activated upon a terminal diagnosis.

Durable Power of Attorney for Health Care Weaknesses

- The agent is named but not often given adequate guidance regarding the person's wishes and choices for care.
 - They are often ineffective in emergency situations.
 - Practitioners often follow routine protocol without consulting the agent.
 - The durable power is effective only upon incapacity of the patient, rather than in diminishing states (most common for those affected by dementia).

"Do-Not-Resuscitate" Weaknesses

- A DNR is difficult to honor in emergency situations, especially pre-hospital or out of hospital.
- DNRs are often misunderstood as a blanket healthcare directive to limit treatments other than cardio-pulmonary resuscitation (CPR).
 - DNRs are limited in scope to specific heart/lung failure, rather than other conditions.
 - A DNR may or may not be understood or agreed to by the agent or proxy decision-maker named in a durable power of attorney for health care (DPOAHC).
 - DNRs often do not transfer well between settings.

chronic illness became the leading cause of death in the US.⁷ This living at the end of life with chronic illnesses will continue long into the future. Most of us will die of complications from chronic illnesses, often with slow and uncertain disease paths affected by dementia while being caregiver dependent.

The Barriers and Concerns

Since the tragic case of Terri Schiavo captured media attention and America's legal and political spotlight, significant focus nationwide has been given to legislative proposals to address/prevent similar situations. Unfortunately, the complex ethical issues of self-determination, surrogate decision-making and judging between terminal vs. disabled states, when reduced to sound bites, remain divisive. Well-intentioned legislative solutions need to be carefully crafted to find common ground.

In addition, public policymakers and healthcare ethicists have studied the reluctance of Americans to implement advance directives and, in recent months, identified a number of barriers as to why more Americans don't complete advance directives.

Those issues include:

- Documents cannot anticipate unknown future clinical situations or medical conditions, nor clarify unclear preferences.
- Treatment preferences cannot be clearly conveyed in a brief, "check box style" format.
- Too often, individuals do not talk about their choices with healthcare providers and family members.
- The result of poor communication is that there is little effect on surrogate decision-making and little impact on care for incompetent patients.

Surrogates then act in the "best interest" rather than in substitution of the patient.

- Side benefits are uncertain.
- Finally, death remains a taboo subject in most homes dominated by the western medical model. As one source put it, "*Americans are the only people on the planet who believe death is an optional event.*"

The Progress

Fortunately, the reluctance of Americans to discuss advance care planning with their professional caregivers has received attention at the national level. Proposed legislation is currently under consideration by Congress allowing for Medicare payments to physicians for end-of-life consultations. While that legislation is uncertain, given the current fiscal environment, it nonetheless attempts to address the concern directly.

In addition, there has been a surge in the numbers of Americans reportedly completing advance directives as a direct result of the Terri Schiavo case. Some estimates say that as many as 25% of Americans may now have them in place (a 67% increase in less than a year).

Several national and state electronic repositories have recently been established. These repositories hold electronic versions of advance care documents for patients and agents. Current utilization, though limited, is growing. Web-based retrieval helps remote family members and professional caregivers when the information is not with the patient or a hard copy cannot be located.

Forms for naming an agent at the time of the document's execution, rather than waiting for complete patient incapacity, are becoming more commonplace as well. Specific statutory language however, may need to be revised.

The Recommendations

I. Reduce barriers to advance care planning document retrieval

Explore state initiatives (e.g. Arizona, North Carolina, Vermont, West Virginia) regarding statewide efforts to encourage electronic storage and retrieval of advance care planning documents.

II. Change and Revise Policies

Allow for the appointment of durable powers of attorney prior to incapacity if a person so chooses. To protect the interests of all patients, surrogate decision-makers should, at a minimum, meet the requirements set by guardianship statute to involve the patient appropriately in all healthcare decisions related to their care and treatment.

Respect and honor the wishes of all persons. Kansans are encouraged to make their wishes clear via verbal and written directives and by naming a durable power of attorney for health care. Healthcare providers are encouraged to initiate these conversations with patients.

Ensure that all persons, including minors, have access to life-sustaining treatments inside and outside of medical settings based on their family and physician decisions.



Left: A sample Physician's Order for Life Sustaining Treatment form. To review a sample POLST form, contact life@lifeproject.org.

Proactively address the growing variety of life-sustaining measures (beyond cardio-pulmonary resuscitation) to ensure that chronically ill and dying persons are afforded appropriate comfort measures and non-burdensome treatments.

Explore and study the Physician Order for Life Sustaining Treatment (POLST) form or one of its iterations. These forms encourage important conversations between healthcare providers and patients and address the appropriateness of critical interventions for seriously ill patients. This may not require statutory change, as evidenced by the State of Oregon.

Protect disabled and cognitively impaired persons regarding their end-of-life wishes and work to assure that these wishes are appropriately expressed and honored.

Conduct a comprehensive review of all Kansas statutes regarding end-of-life care, including access to palliative care, advance directives, appointment of agents, in and outside of medical facility healthcare directives (and physician orders), organ donation, and disposition of the body to determine need for additions, updating or revisions.

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John Carney, Vice President on Aging and End of Life, the Center for Practical Bioethics, presents an overview of the issues to state leaders during the September 29 public policy forum.

Artificial Nutrition and Hydration: Choices and Obligations

With the advance of medical technology, the possibility of sustaining and maintaining human functions has clouded the definition of what it means to be alive. While the Constitutional right to refuse treatment may remain a “settled” matter, continuing to provide nutrition to someone in a permanently unconscious state whose wishes are indiscernible or unknown can deeply divide families, voters, courts and elected officials.

Central to the controversy surrounding Terri Schiavo’s case were the differing interpretations of her preferences for treatment—being fed indefinitely via artificial nutrition and hydration. There were questions about her expressed wishes, because she did not have written advance directives. There were challenges

made to the diagnosis of persistent vegetative state, argued by some to be a terminal condition, though not imminently life-threatening and resulting in endless legal motions and court proceedings. Disability rights groups also argued that Terri’s “disability” demanded special protections in order to ensure that her life, however compromised, was not cut short.

“Continuing to provide nutrition to someone in a permanently unconscious state whose wishes are indiscernible or unknown can deeply divide families, voters, courts and elected officials.”

A number of public policy questions rise from the heart of these issues. Not only do we struggle with whom should make the decision, we also struggle with making the “right” decision, in ensuring the state’s interest to protect those who cannot speak for themselves and in reconciling the deeply personal and emotional struggle resulting from withholding and withdrawing

treatments.

The Problem

The difficulty in developing sound public policy related to the administration of artificial nutrition and hydration – especially for those under the protection of the state who cannot speak for themselves - is to balance the private interests of individuals with the public good. The weighing of the benefits and burdens of each must be considered on an ongoing basis. Rights of privacy and personal protection address not only self-determination, autonomy, pursuit of meaning and the definition of life itself, but encompass broader dimensions of society and culture (community standards). The problem of balance involves religious and spiritual values, existential and economic considerations and convictions about the role and obligation of government to intervene and provide support to those in need.

The issue is also one of medical vitalism, which refers to attempts to preserve the patient’s life in and of itself without any significant hope for recovery.¹ Many faiths, including the conservative Catholic tradition, reject this position and, instead, argue for a “purpose in being” that goes beyond mere bodily function. Some disability groups argue that quality of life is relative in nature and that no one can judge for another about their quality of life.

Unfortunately, existing medical technology now possesses the capabilities of indefinitely maintaining life functions for those who have no medically based expectation of recovery. The problem, then, in this light is not so much about balancing the rights of privacy in administering or withholding treatment as it is about the definition of life itself and the obligations and limits of government to protect those interests, especially for those who cannot speak for themselves.

The Barriers and Concerns

For most Americans, healthcare is a private matter between doctor and patient and between patient and family. Across the political spectrum, government’s insertion or “intrusion” in private matters is for the most part considered unwarranted. The exceptions deal primarily with protections for the vulnerable.

Generally, matters of life and death decision-making are left to healthcare professionals and the patients and families they serve. These decisions are governed and protected by professional licensure laws, scope of practice and certification standards and accreditation.

Disagreements about end-of-life treatment directives get resolved at the bedside in most cases. It is in the cases where irresolvable disputes arise that the legal system gets involved. Every effort should be made to determine the patient's wishes, especially as the patient's capacity diminishes, burdens of treatment increase, and locations of care become less acute.

In addition, unforeseen and unanticipated developments in technology and medical interventions require the need for a trusted surrogate to be named and to be familiar with the wishes of the patient

when he/she can no longer speak.

Post-Schiavo attention by medical practitioners to artificial nutrition and hydration (ANH) underscores that a decision to administer ANH involves “substantial risks and burdens” to the patient and in nearly every case is not judged an emergency.² Weighty consideration about the treatment goals should accompany any recommendation or request.

“Disagreements about end-of-life treatment directives get resolved at the bedside in most cases. It is in the cases where irresolvable disputes arise that the legal system gets involved.”

The Progress

In 2002, Kansas legislators approved a completely revised Kansas Guardianship statute. While most guardians are family members already, provisions in the new law require guardians to get to know their wards similarly to the ways that family members know one another. This statute also requires guardians, to the best of their ability, to make end-of-life decisions for their wards that reflect the wishes of the ward (substituted judgment). When that cannot be achieved, the guardian is required to make decisions in the ward's "best interest," in consultation with medical professionals. Revisers of the statute took into consideration that end-of-life decisions were, first and foremost, personal and family decisions and then medical decisions. Obligations of guardians and professional caregivers were assumed to protect the interests of the ward.

In the summer and fall of 2005, a committee of the Kansas Judicial Council studied the statutory language governing the authority and responsibility of guardians in making decisions about administering artificial nutrition and hydration for wards of the court. The group's recommendations will be forwarded to the legislature when it returns in 2006.

Statutory language for the provision of ANH for persons who do not have an advanced directive in place at the time of incapacity has been proposed by some states.

The Recommendations

I. Support the Kansas Judicial Council recommendation on clarifying language regarding the obligations of guardians on the administration of artificial nutrition and hydration (ANH) for wards of the court.

II. Provide opportunity and hearing for parties interested in developing statutory language in the provision of ANH for all Kansans without a durable power of attorney for health care (DPOAHC) or advance directive should their health condition warrant.

III. Conduct a comprehensive review of all Kansas statutes regarding end-of-life care to determine need for additions, updating and/or revisions. This review should include a review of access to palliative care, advance directives, appointment of agents, in and outside of medical facility healthcare directives and physician orders, organ donation and disposition of the body.

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The LIFE Project would like to acknowledge Bob Twillman, Co-Chair of the LIFE Project Pain Management Task Group and Pain Management Program Director at the University of Kansas Medical Center, and John Carney, Chair of the LIFE Project Public Policy Task Group and Vice President on Aging and End of Life at the Center for Practical Bioethics, for their expert contributions to this publication.

Published January 2006

**Funding for this project is provided in part by a grant from the American Alliance of Cancer Pain Initiatives (AACPI),
University of Wisconsin-School of Medicine, Madison, WI**

Other Acknowledgements:

The LIFE Project gratefully acknowledges additional funding and support from United Methodist Health Ministry Fund, K.T. Wiedemann Foundation, Harry Hynes Memorial Hospice, Foundation for Hospice Care, Kansas Department on Aging, PhRMA, Kansas City Cancer Center, Northwest Kansas AHEC, Lighthouse Hospice, Kansas Association of Family and Community Education and Midland Hospice.

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