

The Missouri End-of-Life Coalition was formed in 1998 in response to a call from the Robert Wood Johnson Foundation (RWJF) for state-based coalitions to improve the healthcare of seriously ill and dying patients.

The RWJF's interest in improving the healthcare of seriously ill and dying patients was sparked by the disappointing results of a large end-of-life care study that it funded. More than 8,000 seriously-ill and dying ICU patients participated in the study; researchers counted breakdowns in communication, calculated the frequency with which aggressive treatments were provided, and catalogued the characteristic traits of the deaths they observed. The results of the study were published in the *Journal of the American Medical Association* in November 1995.

In the first phase of the study, the researchers observed patients dying alone and in preventable pain while attached to unwanted machines. Among other findings:

- Physicians frequently failed to share important medical information with patients and their families or ask about their patient's preferences concerning treatment.
- Do not resuscitate orders weren't issued in a timely manner.
- Dying in an ICU financially devastated many patients and their families.

In the second part of the study, researchers tested two interventions: (1) a group of specially trained nurses facilitated communication among physicians, patients, and their families; and (2) physicians were offered access to computer-generated prognostic information. When these interventions failed to improve the outcomes observed in phase one, RWJF set a national end-of-life care policy agenda to address the problems documented by the study.

In November 2002, RWJF published *Means to a Better End*, a state-by-state report of progress on its policy agenda. Dr. Deborah Parker Oliver reviewed Missouri's progress on the RWJF policy agenda in a plenary presentation at the statewide end-of-life policy summit meeting.

Two reports published in the fall of 2005, looked at the present state of end-of-life care in the United States.

In September the President's Council on Bioethics published *Ethical Caregiving in Our Aging Society*. That report used our aging demographics, experience with advance directives, and the methodologies

caregivers use to make healthcare decisions as the basis for the following conclusions about end-of-life care:

- In clinical settings the goal of ethical caregiving is to benefit the life the patient still has.
- Clinicians are ethically bound to forego life sustaining treatments that are unduly burdensome to the patient being treated.
- Healthcare treatment directives are limited and flawed instruments for addressing most decisions that caregivers must make.
- Proxy-appointing directives are often useful.
- Policies and procedures are needed to encourage ongoing discussion and coordination among patients, clinicians, and caregivers.
- Ethics committees should focus on ensuring patient-centered care.
- Providing good long-term care requires willing, able caregivers, community supports, and supportive laws and social policies.

In November a leading bioethics organization, the Hastings Center, published *Improving End of Life Care: Why Has It Been So Difficult?* The report suggested specific steps for improving care at the end-of-life:

- Approach end-of-life care from a less individualistic, more family oriented perspective.
- Reevaluate advance directives and surrogate decision making to more adequately and routinely factor in information that physicians are comfortable with.
- Make bioethics mediation and conflict resolution available in all healthcare institutions.

The conclusions of the President's Council on Bioethics and the Hastings Center are updates to the end-of-life policy agenda set by RWJF.

The setting for Missouri's first end-of-life policy summit was further energized by Terri Schiavo's case, the Medicare Part D prescription benefit, and Medicaid reform any or all of which might influence the end-of-life policy agenda identified by the summit process.

Missouri's End-of-Life Care Policy Summit

In the spring of 2005, Terri Schiavo's contentious front page dying opened a public debate on end-of-life care policy in Missouri unlike any seen since Nancy Cruzan's death in 1990. To further the dialogue that the Schiavo case sparked, the Missouri End-of-Life Coalition sponsored Missouri's first End-of-Life Policy Summit. The Summit consisted of regional town-hall meetings, a statewide meeting, and this report.

- **Town Hall Meetings**

In preparation for the statewide policy summit meeting, the Missouri End-of-Life Coalition co-sponsored town-hall meetings in Columbia, Jefferson City, Kansas City, St. Louis and Springfield at which citizens were invited to express their concerns about and recommend ways for improving the quality of end-of-life care in Missouri. Patients and patient advocates, caregivers, healthcare providers, healthcare policymakers, legislators, administrators, and citizens participated in the meetings.

Participants in every town hall meeting talked about the need for improved communication among physicians, patients, and families.

Sally Tureman, a citizen-participant in the Kansas City town hall meeting, reported an innovative medical education program that is improving the prospects for better communication between physicians and their older patients. The year-long program pairs every first-year medical student at the University of Missouri – Kansas City with a resident of John Knox Village, the retirement community where Sally lives. Students and villagers become acquainted and find common interests. They develop, perform, and report a project based on a shared interest. The premise of the program is that if medical students learn that they share interests with older people and can work effectively with them, then, as physicians, they will communicate more completely and better serve their older patients. It will take time before the program's success can be measured, but initial reports from participating medical students are promising.

Ms. Tureman's report is a reminder that good policy work includes taking an occasional flyer on an initiative that addresses a big and historically intractable issue even if it can't pay dividends in the current funding cycle.

Other issues raised by town hall participants:

Access and Reimbursement

- Reimbursement drives usage – unless palliative care is reimbursable, it will be underutilized.
- The Medicare and Medicaid hospice benefits must be preserved.

Caregivers and Caregiving

- Caregivers and families still have problems talking about death and dying.
- Healthcare professionals intimidate caregivers.
- Caregivers have unmet psychosocial and spiritual needs.
- Volunteer family caregivers cannot bail-out our bankrupt healthcare system.
- There aren't enough volunteer family caregivers to meet the "boomer" generation's need for caregivers.
- Caregivers need job protection.

Healthcare Decision Making

- There are problems with advance healthcare treatment directives. Often they are either too specific or too vague to be useful.
- People need to do advance care planning and complete durable powers of attorney for healthcare decisions.
- Physicians need to be more involved in their patients' advance care planning – encouraging it, asking about it, even facilitating it.
- Missouri needs a healthcare decisions law to guide the identification of appropriate surrogate decision makers.
- There should be a place for families in end-of-life healthcare decision making.
- As progressive dementia becomes commonplace, our either/or model for decisional capacity/incapacity becomes increasingly problematic. A new model that incorporates the reality of partial or incomplete capacity ought to be adopted.

Palliative Care

- Patients, families, and physicians need to be talking with each other about palliative care – what it is, who provides it, how it is paid for.
- Nursing homes need to be palliative care experts.

- We need more physicians who are trained in palliative care.
- Most emergency service providers do not have protocols for respecting do not attempt resuscitation orders.
- Good palliative care should not be dependent on a hospice referral.
- Hospice referrals should be timely.
- Fear of criminal prosecution compromises effective pain management.
- **Statewide Summit Meeting**

The Missouri End-of-Life Coalition’s 2005 statewide end-of-life care policy summit was held in Jefferson City, October 6, 2005. Participants in the summit included lawmakers, educators, policymakers, advocates, healthcare providers, citizens, and state employees. The format for the summit included plenary and breakout sessions in which participants provided perspectives, raised issues, and suggested solutions.

The policy summit was moderated by Jonathan Keyserling, Vice President – Public Policy, The National Hospice and Palliative Care Organization, Alexandria, Virginia. Plenary presentations were made by Charles Sabatino, JD, Director – Commission on Law and Aging, American Bar Association, Washington, DC; Debra Parker Oliver, PhD, Assistant Professor, University of Missouri School of Social Work, Columbia, Missouri and current chair of the Missouri End-of-Life Coalition; and Steven Zweig, MD, MSPH, Professor and Associate Chair, Co-Director – Family Medicine Fellowship Program, and Medical Director – Care in Aging Program, University of Missouri School of Medicine, Columbia, Missouri and former chair of the Missouri End-of-Life Coalition.

Mr. Sabatino provided a nationwide perspective on end-of-life care issues. His presentation highlighted the emergence of health care decision-making laws that address a number of end-of-life care issues in a single statute and the palliative care-supporting activities of the Federation of State Medical Boards, the National Quality Forum, and the National Association of Attorneys General.

Dr. Parker Oliver provided the Missouri perspective on end-of-life care issues. Her report based on the *Means to a Better End Report* (2002) and the results of her own research, compared Missouri’s progress on the RWJF end-of-life care policy agenda with the progress by other states. The *Means to a Better End Report* used eight measures to grade the states’ progress on end-of-life care policy. Missouri’s grades for each of the measures:

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| • Advance directive policies – “C” | • Hospice use – “C” |
| • Location of death – “D” | • Hospital end-of-life care services – “C-” |

- Care in ICUs at the end of life – “C”
- Pain among nursing home residents – “C”
- State pain policies – “B”
- Palliative care-certified physicians and nurses – “D”

Dr. Zweig offered a Missouri physician’s perspective on end-of-life care. In his presentation he offered a four-step process for patient-centered care of seriously ill and dying patients: (1) identifying patient preferences, (2) informing patients about their medical prognosis, (3) defining the goals of patient-care, and (4) implementing a management plan that is consistent with these goals. According to Dr. Zweig this process helps patients recognize the limits of disease oriented medical care, fosters support for palliative care (including professional training and reimbursement), and results more patient-centered care of seriously ill and dying patients.

Summit attendees participated in a breakout session in which they discussed one of the following topics: access to and reimbursement for quality end-of-life care, caregivers and caregiving, healthcare decision-making, and palliative care.

In the access and reimbursement session, a group of hospice executives discussed tensions in the relationships between their organizations and the financial intermediaries that administer the Medicare hospice benefit. The discussion was an important reminder that issues about end-of-life care cannot always be framed in terms of the care provided to a particular seriously ill and dying patient. Our grasp of end-of-life care is maturing. As it becomes more systematic, there will be many policy issues for which the appropriate frame is the system of end-of-life care, rather than an individual patient. Though system issues are unlikely to have a human face – as Karen Quinlan, Nancy Cruzan, and Terri Schiavo certainly did, the policy responses to systems issues will affect end-of-life care at bedsides across Missouri, throughout our region, and nationwide.

Policy advocates need to develop their ability to present complex issues to policymakers in ways that are simple but not simplistic. Unless both policy advocates and policymakers exercise self-discipline, the economic considerations freighted by these system issues will overwhelm the issues themselves.

Other issues raised by Summit participants:

Access and Reimbursement

- Reimbursement for palliative care discussions with doctors.

- When patients routinely move from one insurance plan to another – physician/patient relationships suffer.
- Reimbursement drives usage – unless palliative care is reimbursable, it will be underutilized.
- The Medicare and Medicaid hospice benefits must be preserved.

Caregivers and Caregiving

- Caregiving is not appreciated or compensated adequately in our society. We are approaching a critical shortage of caregivers as the population ages and most healthy adults are and must be working. We also value independence, which makes it difficult for patients to accept care when needed.
- Employees need workplace policies that support family caregivers and provide grief counseling.
- Family caregivers, particularly those whose patients aren't receiving hospice or home care support, need caregiver training.
- Caregivers need adequate reimbursement for their work and family caregivers need access to respite, so that they can continue to manage the burden of care.
- Patients/families and providers need more education on palliative care. Earlier conversations about reexamining the goals of care as illness advances need to be encouraged, for example, by providing payment to physicians for office visits related to advance care planning. Patients and families need to understand that accepting palliative goals does not mean giving up or dying right away.
- Supplement the end-of-life care infrastructure with community volunteers. The Older Volunteer Service Bank and Circles of Care are two proven models for engaging such volunteers.
- Missouri needs a Physician Orders for Scope of Treatment law to support palliative care in non-hospital healthcare settings.

Healthcare Decision Making

- Advance treatment directives are frequently too specific or too vague to be useful.
- People need to do advance care planning and complete medical powers of attorney.
- Physicians need to be more involved in their patients' advance care planning – encouraging it, asking about it, and facilitating it.

- Public and professional education concerning advance care planning and palliative care should be widely available.
- Missouri needs a healthcare surrogacy law.
- Families need a place in the decision-making model for end-of-life care.
- Assuming patients either have or don't have decision-making ability doesn't accommodate the reality that many seriously ill and dying patients have progressive dementia. We need a healthcare decision-making model that provides for patients who have incomplete capacity.

Palliative Care

- Patients, families, and physicians need to talk with each other about palliative care – what it is, who provides it, and how it is paid for.
- Nursing homes need to be palliative care experts.
- Palliative care training for medical, nursing, and social work students is inadequate.
- Most emergency service providers do not have protocols for respecting do not attempt resuscitation orders.
- Good palliative care should not be dependent on a hospice referral.
- Frequently hospice referrals are not timely.
- Fear of criminal prosecution compromises effective pain management.

Improving End-of-Life Care for All Missourians – *Building a Policy Agenda*

Focus on the Big Idea – Palliative Care

In a 1997 editorial in *Nursing Home Medicine*, Dr. Zweig, wrote about the lessons to be learned from the SUPPORT study.

“SUPPORT,” Dr. Zweig said, “displays the failing of talking to one patient at a time and of communicating with each physician about one patient at a time. SUPPORT failed because the culture of the hospital didn't change.”

In the past ten years, palliative care has been transformed from a synonym for “comfort care” into a structural framework in which the cultural change referred to by Dr. Zweig is occurring. In 1995, the usual definition for palliative care was “medical care that concentrates on reducing the severity of disease

symptoms rather than curing the disease.” The National Consensus Project for Quality Palliative Care (2004) provides the following definition for palliative care:

The goal of palliative care is to prevent and relieve suffering and to support the best possible quality of life for patients and their families, regardless of the stage of their disease or the need for other therapies. Palliative care is both a philosophy of care and an organized, highly structured system for delivering care. Palliative care expands traditional disease-model medical treatments to include the goals of enhancing quality of life for patient and family, optimizing function, helping with decision making, and providing opportunities for personal growth. As such, it can be delivered concurrently with disease-model medical care or as the main focus of care.

The maturation of the palliative model of medical care is transforming both the delivery and the receipt of end-of-life care. Policy initiatives that fit with or naturally extend palliative care are most likely to improve end-of-life care not only in the specific ways they address patient care, but also in larger ways by making incremental contributions to a culture that places a high value on end-of-life care. Support for the palliative model of medical care should be the number one item of Missouri’s policy agenda for end-of-life care.

A Policy Agenda to Improve End-of-Life Care for All Missourians

- Support the palliative model of medical care
- Survey Missouri’s citizens and healthcare providers about end-of-life issues
- Determine who is authorized to make healthcare decisions for persons who cannot personally participate in those decisions
- Support legislative initiatives to improve end-of-life care
 - Adopt a way for palliative care orders to travel with the patient across the continuum of care
 - Find a reliable way to document decisions about resuscitation orders in nonhospital settings

Connect / Reconnect the Dots

Formerly, when palliative care experts talked about timely redirection of care from the disease model to the palliative model, the performance of surgical procedures was taken as proof that care had not been redirected. Today, the redirection of care is no longer a bright-line event – palliative and disease model medical cares are delivered concurrently. Formerly, “palliative-surgery” was an oxymoron, now it is commonplace. The salient traits of palliative medical care are changing in fundamental ways. Yesterday’s reliable indicators of quality palliative care may already be obsolete. To maintain their focus on palliative care, policymakers need to continuously reconnect the dots.

Sweat the Details

In an article for the journal *Bioethics Forum*, Doug McNair, an executive with Cerner Corporation, the Kansas City-based healthcare information technology company, wrote that “a postmodern concept of quality implies the notion of repeatable, universalizable intention toward desired outcomes. This type of quality is reproducible in the small, time and again.”

Palliative care is not only a big idea. It is also a system for providing care. Palliative care functions or dysfunctions based on the repeatable, universalizable intention of human persons toward the interconnected elements of the palliative care system.

Recognizing pain as the fifth vital sign was good palliative care policy. However, you don’t have to watch very many very frustrated patients trying to rate multiple-dimension pain on a ten point scale or watch very many nurses roll their eyes as they record the pain scores their patients provide to know that the value of recognizing pain as the fifth vital sign is not being realized where it counts – at the individual assessment level. Well-made end-of-life policies promote clinical articulation – sweating the details is essential.

Listen to and Respect Every Citizen, Healthcare Provider, and Policymaker

Prior to Terri Schiavo’s death, neither Missouri’s lawmakers nor its citizens had been asked to contribute much to the emergence of palliative care as the conceptual framework for excellent end-of-life care. Immediately following the death of Terry Schiavo a flurry of end-of-life care legislation was introduced in

the Missouri General Assembly. Some of these legislative threads were picked up when the General Assembly reconvened in 2006. It is clear that Missouri's lawmakers are no longer on the sidelines; they have become active participants in making the policies that will determine how Missourians are cared for at the end of life.

The End-of-Life Policy Summit invited Missouri's citizens and lawmakers to become vigorously involved in the policy issues that are raised by the promise of palliative medical care. The promise of palliative care for seriously ill and dying patients cannot be realized in Missouri until we tack-down who is authorized to make healthcare decisions regarding the care of people who cannot personally participate in those decisions and by what standards are such decisions to be made. The gap between the healthcare directives that citizens make and operationalizing those directives needs to be closed. A way for palliative care orders to travel with a patient through our fragmented continuum of care needs to be adopted. We need a reliable way to document decisions about whether or not to attempt resuscitation in non-hospital settings. The tension between healthcare and law enforcement interests regarding the prescription of narcotic drugs needs to be relieved.

Many of the same issues were raised first by the citizen-participants in the town hall meetings and then by the policymakers and healthcare providers who participated in breakout sessions at the statewide end-of-life care policy summit. Although town hall meetings are not research, the impression of a radical consensus among Missourians who are interested in improving end-of-life care about the policy issues that need to be addressed is undeniable. Verifying this consensus by surveying cross-sections of Missouri's citizens and healthcare providers would create a powerful advocacy tool for the people's end-of-life care policy agenda. Regardless of the findings, such surveys would inform and add weight to the work done at future Missouri End-of-Life Care policy summits. Conducting such surveys and sharing the findings with policymakers should be a key item of Missouri's end-of-life care policy agenda.

Missouri's end-of-life care policy agenda also includes two pending legislative initiatives that are supported by the Missouri End-of-Life Coalition:

- MO HB 1506 the Missouri Physician's Orders for Scope of Treatment Act addresses three issues that will help Missouri physicians care for their sickest patients: (1) the need for emergency medical service providers to honor physician orders not to attempt resuscitation; (2) the need to operationalize the advance directives of very sick or dying patients who can no longer participate

in their healthcare decision-making; and (3) the need for physician orders that remain in place as patients move from healthcare setting to healthcare setting (clinic, hospital, nursing home, home).

- MO SB 566 act authorizes an advanced practice registered nurses to prescribe schedule II, III, IV, or V controlled substances under a collaborative practice agreement with a licensed physician.

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