

The Kansas LIFE Project—Living Initiatives for End-of-Life Care

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ABSTRACT

Background: Numerous studies continue to demonstrate the needs for improved palliative and end-of-life care.

Objective: Kansas stakeholders joined together, under the leadership of the Kansas Hospice and Palliative Care Organization (formerly the Association of Kansas Hospices) in 1997, to improve palliative and end-of-life care for Kansans living with advanced chronic and terminal illnesses.

Design: The Kansas LIFE Project (Living Initiatives for End-of-Life Care) plans and implements strategic initiatives and projects that engage public policy leaders, healthcare professionals and Kansas citizens.

Setting: Grassroots community coalitions, LIFE Project Caring Communities, have been developed, supported, resourced, and maintained as a core strategic and action tool for assuring that local and state progress is achieved and meaningful and relevant to Kansas citizens.

Conclusion: Local community coalitions have the best understanding of citizen needs and are important to include in state-level planning and action in ways that lead to successful, meaningful and relevant outcomes for improved care for citizens living with advanced chronic and terminal illnesses. With adequate support and strong leadership, local coalitions can effectively leverage their presence and “ownership” of communities to drive change among health care professionals, policy leaders, and citizens.

THE STATE PARTNERSHIP

IN FEBRUARY 1998, as a result of both Kansas' statistics and national studies such as SUPPORT,¹ the Kansas Hospice and Palliative Care Organization (KHPCO) convened an educational and informational meeting in Topeka, Kansas, to begin examination and discussion about issues related to end-of-life care. KHPCO saw the need to take initiative to create awareness beyond its membership and to stimulate cooperative action among many stakeholders. Professional leaders

from all disciplines attended and indicated interest in ongoing engagement in active efforts to address end-of-life care issues. This group continued to meet each month, studying the state of end-of-life care, determining needs, exploring current services and discussing concerns, hopes and challenges. Group participants continued to invite others to join the effort. Currently, more than 100 groups are LIFE Project Partners.²

The LIFE Project Partners share the mission of helping Kansans with advanced chronic and terminal illnesses live with dignity, comfort, and

peace. The vision of the LIFE Project is that Kansans understand their choices in care, share their wishes and choices with others, and have their choices honored. Early on, the LIFE Project Partners created three guiding documents on principles of palliative care, pain management and advance care planning. The work of the LIFE Project focuses in three key areas: creating an environment of public policy that promotes and encourages quality care; creating expertise in health care professionals and systems; and engaging, empowering, and activating citizens. Three primary Task Groups were created—one for each of these three strategic areas. With a 1-year planning grant from The Robert Wood Johnson Foundation, in 1999, the Task Groups developed plans for implementing specific initiatives. A steering committee, comprised of the leaders of the three major task groups and the staff for the project, was developed to direct and coordinate the project. The Kansas Hospice and Palliative Care Organization then received a three-year implementation grant from The Robert Wood Johnson Foundation's Community-State Partnership program. Additional funding came from the Kansas-based United Methodist Health Ministries Fund and a pledge of support was secured from the Kansas Association of Broadcasters.

The Task Groups

The Public Policy Task Group designs, implements, and evaluates numerous initiatives including, to date: creating a monograph drawing attention to the need for improved care at the end of life and the challenges to be faced³; auditing Kansas statutes to identify and address barriers to providing quality end-of-life care; encouraging and securing better data collection; tracking legislative and regulatory developments; offering expert testimony to numerous committees and task groups of the Kansas legislature; working with the Kansas Judicial Committee related to guardianship provisions and the Durable Power of Attorney for Health Care; creating materials to encourage advance care planning; encouraging and assisting in the issuance of joint pain management guidelines by Kansas licensing boards; convening of key leaders in public policy forums; and encouraging collaboration and communication to maximize scarce resources.

The Professional Education Task group is active in numerous areas, including: offering pro-

fessional education to create a cadre of Kansas health care professionals trained in pain and symptom management; offering palliative care, Education on Palliative and End-of-Life Care (EPEC) and End-of-Life Nursing Education Consortium (ELNEC) training across the state; leading a bistate tele-hospice project; creating manuals and training programs on system-wide improvement of pain management for acute and long-term care agencies; creating and overseeing a pain protocol project to learn about changes in healthcare systems; addressing attitudes and perceptions via creating and sponsoring "Stories at Work" with the Kansas Humanities Council; and, offering speakers and materials to many other groups and organizations who provide education to health care professionals.

The Public Engagement Task Group, aware of the critical role of citizen engagement and action, focuses on the creation and implementation of a comprehensive design to mobilize and utilize grassroots efforts. Community leaders from all across Kansas were recruited to establish local consumer advocacy and action groups focused on improving end-of-life care. This design of grassroots action centers on the creation, support and resourcing of community-based action groups, the Kansas LIFE Project Caring Communities. LIFE's goal, during the planning year of 1999, was to facilitate the formation and training of 12 of these Caring Communities to work in partnership with the state organization representatives in development and implementation of local activities to improve end-of-life care.

THE LIFE PROJECT: KANSAS CARING COMMUNITIES

The birth and evolution of the Kansas Caring Communities grew from an intrinsic belief that sustained local efforts are fundamental for improving end-of-life care. To know that the strategies and initiatives of the LIFE Project are grounded and meaningful, input from citizens across the state is important. Furthermore, it is the citizens who must implement them. This dual engagement of statewide entities and local coalitions is a cornerstone of the LIFE Project's work and action.

LIFE Project Caring Community leaders were recruited via personal solicitation, using contacts already established through KHPCO. KHPCO

had worked intentionally to ensure that the LIFE Project involve many stakeholders and felt it important that these local groups also work to be very inclusive, collaborative and representative of the broader community. Each Caring Community was asked to meet several conditions and share several common goals. These included accepting the responsibility:

- To share the mission of helping Kansans living with advanced chronic and terminal illnesses to live with dignity, comfort and peace.
- To convene a Caring Community Council that includes leaders from acute care, home health, hospice, long-term care, faith communities, business community, and consumers.
- To agree to participate in ongoing training, annual meetings and communication efforts.
- To provide two key contact leaders to the LIFE Project and assure that these leaders serve as teachers and communicators to the LIFE Project and teachers and communicators for the LIFE Project.
- To serve as advocates for all Kansans nearing the end of life.

This recruitment process resulted (by 2004) in 34 local grassroots LIFE Project Caring Community Councils.⁴ In February 2000, The Life Project sponsored the first training retreat to launch the Caring Communities. A variety of presentations, group discussions and resources were offered to 80 participants. Sessions provided basic information about end-of-life issues, tools for conducting a community assessment and time to develop strategies. Each community received a “tool chest” of books and resources. More than 90 Caring Community leaders participated in an August 2000 training day, and more than 100 in an April 2001 and October 2002 training.

The first Caring Community leaders (in 2000) developed their local councils, working to understand more fully the current status of end-of-life care in their communities. Furthermore, they agreed to participate in supporting the Public Broadcasting Service’s airing of the Bill Moyers’ *On Our Own Terms* series by highlighting issues related to end-of-life care, raising awareness of citizens, creating dialogue between the LIFE Project and Kansans and increasing viewership of the series.

From the February 2000 retreat forward, the input, learning and expertise of the Caring Com-

munities has both shaped and informed the work of the LIFE Project. The Caring Communities provide key leadership in reaching the citizens of Kansas. When the statewide organizations work, as LIFE Project Partners, to create strategic action plans, it is the Caring Community Councils that ensure the plans are successfully completed on a local level. Caring Community leaders serve as the voices of local needs and issues, assuring that statewide efforts meet the needs of citizens all across Kansas. Likewise, the Caring Communities have been shaped and informed by the efforts of the various LIFE Project Task Groups. When the Caring Community Councils identify needs and issues, the LIFE Project Task Groups work with and through the Caring Communities in order to create tools and strategies for addressing these needs.

Caring Communities vary, of course, in terms of individual group impact and intensity. Even within a given community, the action and engagement of the Caring Community Council may vary greatly from one season to the next. The tasks and roles of the Caring Community Councils are dynamic and continue to grow and change, as does the LIFE Project. These coalition leaders provide input that represents the diversity of needs across the state. It is these leaders who help the LIFE Project make decisions and take action that serves the needs of all Kansans. Grassroots input, direction, leadership and affirmation remain critical to LIFE Project success. Because this symbiotic partnership yields stronger community action and statewide advocacy for quality care at the end of life, efforts to create and sustain additional Caring Communities continue.

All of the original Caring Communities, although at different stages of development and action, continue to serve their citizens. Additional Caring Communities have emerged, with 34 LIFE Project Caring Communities now active. Although none of the communities has a regular source of funding, several have sought funding for special projects. All of the Caring Communities work together to maximize the LIFE Project’s budget for community engagement and action.

As advocates for all Kansans nearing the end of life, the LIFE Project serves as the key link of information, support, and resources for Kansans, and those who care for and about them, who are living with advanced chronic and terminal illnesses as they near the end of life. Although

quantitative data alone does not measure the overall impact of social change, we do know that consumers and health care professionals are using the LIFE Project services and products. The demand for LIFE Project support, services, resources and materials continues to grow. During 2000–2003, the LIFE Project:

- Created, produced, and supplied resource materials including information about end-of-life care, advance care planning, and pain management. More than 180,000 copies of these materials were provided, on request, to Kansans, LIFE Project Partners and LIFE's Caring Communities.
- Launched a toll-free Consumer HelpLine and Pain Management Hotline in September 2000. LIFE receives an average of three calls per week from consumers seeking information and assistance with concerns about end-of-life care.
- Engaged Kansas broadcasters in sharing information about end-of-life care with Kansans.

The LIFE Project is deeply grateful for the partnership of the Kansas Association of Broadcasters who have shared the mission and vision of our work. This key LIFE Project Partner pledged to share significant airtime with the LIFE Project and engaged its members in promoting our public engagement campaigns. In 2001 and 2002, members of the Kansas Association of Broadcasters aired 2683 television spots and 32,952 radio spots, for a total value of \$409,541. In 2002, the LIFE Project also aired radio interviews on 62 Kansas stations that reached 76,100 people.

CHALLENGES

With the wide variety of communities, groups and individuals doing the work of the LIFE Project, it is challenging to keep everyone moving in the same direction. Although LIFE Project Partners address a variety of issues and concerns, the common concern shared by each is the desire to improve care that Kansans receive as they near the end of life. One challenge we face is the recruitment of the right leadership for the various initiatives. Recruiting new leaders requires aggressive identification and outreach. A regular and ongoing task for the LIFE Project is to scan the identified needs and goals of the LIFE Project and to ask, anew, "Do we have the right people

working on this?" "Are there others who are or might need to be working with us?" And, if so, "How do we bring them on-board?"

Another recurring challenge is to remind LIFE Project Partners of the values of collaborative effort. There are always costs and benefits of working together rather than in isolation. To have a truly shared vision and shared mission, the insights and expertise of each individual, organization and group must be considered.

Another challenge faced was the need for the LIFE Project organizational structure to reflect the broad-based involvement and perspectives of the LIFE Project Partners. In 2002, the LIFE Project, which began as a project of the Kansas Hospice and Palliative Care Organization, became an independent 501(c)3. Kansas hospice leaders recognized and responded to the need to assure that the efforts of the LIFE Project an outcome of many, many groups, be an organization the governance of which reflects that diversity.

A sizeable challenge that the LIFE Project faces is to evaluate what and how the LIFE Project is doing. With a project that is as diverse in partners and project scope as the LIFE Project, examining social change is very difficult. Although the LIFE Project continues to work to engage in meaningful evaluation, we are far from doing it well. While we can track data such as that included here, LIFE does not have the staffing support to collect and compile complete data from 100 LIFE Project Partners and Caring Communities. Nevertheless, LIFE believes that it is important that time and energy be given to systematic evaluation so that our efforts are informed and shaped by the learning we gain along the way.

THE ROLE OF THE PARTNERSHIP

Communication

Throughout the history of the LIFE Project, a great deal of attention has been paid to creating and maintaining a communications strategy that facilitates cooperation and collaboration between and among a growing array of LIFE Project Partners. Several key structural components assist in this process. A LIFE Project staff member assumes responsibility for maintaining regular communication with the leaders of each Caring Community. The Caring Communities share

about their work and what they are learning. Until 2002, these reports were submitted monthly. From this reporting and sharing, the LIFE Project gains a more complete understanding of the community-based forums, discussion groups, press coverage and needs that are being experienced and addressed across the state. In addition, an annual meeting of all LIFE Project Partners provides an opportunity to review the accomplishments and challenges of the previous year and to face the work of the next year.

Internet and electronic tools are integral to statewide communication. Caring Community Updates, an electronic information bulletin, helps the Caring Communities learn from and share with one another, create and implement strategic action that can be occurring simultaneously across the state, and, additionally, provides tools to support the various groups' efforts. Ideas, suggestions, educational opportunities, other findings and needs from the Caring Communities are shared among the task groups to ensure that the LIFE Project is both aware of and engaged in addressing issues that most impact Kansans. Conference calls provide opportunity to learn together about special issues, needs and events.

The *LIFeline* is a periodic newsletter that reports on all LIFE activities and also activities of LIFE Project Partners that are addressing needs of Kansans nearing the end of life. The distribution list of *LIFeline* increased by 50% from 2000 to 2001 and increased another 50% in 2002. Periodic bulletins report on special events, developments or issues. A weekly *Newsflash* helps Partners stay updated on national developments and concerns in end-of-life care. The distribution list of *Newsflash* increased by 15% from 2000 to 2001 and grew another 90% in 2002.

The LIFE Project website, www.LIFEProject.org, is an important tool for communication. As Caring Communities assessed community needs, invited citizens to focus groups, held displays at health fairs, worked together to staff a booth at the Kansas State Fair and worked with media, the Web site grew as a shared resource where any and every community could refer citizens, leaders and media for further information. The Web site continues to grow and includes information for health care professionals, consumers, policy makers and others. The site includes:

- A Caring Communities state map that provides a hyperlink to each Caring Community;
- A resource guide for that community, as prepared by the Caring Community;
- Information on LIFE's speakers bureau and an opportunity to request a speaker;
- Information for consumers, on a variety of issues;
- Information about the LIFE Project's toll-free HelpLine and the statewide Pain Management Hotline;
- Presentations for use with local community groups;
- Links to a variety of resources and to the LIFE Project Partners;
- Information on the latest news about the LIFE Project and a calendar of events;
- Suggestions and aids for beginning conversations about health care choices at the end of life; and
- A variety of consumer resources.

From the creation of the website in September 2000 through December 2003, the LIFE Project website has been visited 62,795 times, with 414,179 hits to various locations within the site. Consumer resources, presentations and other materials have been downloaded in PDF format more than 32,000 times.

Collaboration

LIFE Project Partners and staff provide expertise, information, opportunities for networking, communication and collaboration, as well as an organizational mission and structure to help Kansas communities improve end-of-life care. The Caring Communities provide key leadership in penetrating and impacting local leaders, identifying and utilizing local sources to distribute information and provide education, and guiding the Project Partners in identifying the most successful strategies for creating lasting change. Caring Communities are lead agents in engaging thousands of Kansans in discussion groups, providing information to and through faith communities, libraries, universities, colleges, senior centers, health care provider organizations, civic groups, media, clubs, health fairs, special events and other venues. To assist local leaders in public speaking, the LIFE Project provides them with training, materials and videotapes. Many of these materials are posted on the LIFE Project website and are offered in train-the-trainer and speaker bureau training events. This process of sharing

resources and expertise shapes the work of the LIFE Project and illustrates the dynamic interaction between and among the LIFE Project Partners, Task Groups and the Caring Communities. Following is a list of some of the initiatives that demonstrate the effectiveness of this structure:

- A publication called, *Advance Care Planning: Do It For Those You Love*, created by the LIFE Project, is distributed by Caring Community leaders and used when speaking to groups. It is accompanied by a video, a leader's discussion guide, and an entire toolkit utilized with LIFE's speakers bureau.
- Several LIFE Project Partners, led by the Kansas University Center on Aging, the Kansas Department on Aging and KHPCO, worked to develop an informational wall-chart that addresses end-of-life issues. The wall-charts, displayed in physician offices, examination rooms, pharmacies, senior centers, hospitals, churches, long-term care facilities, libraries, and elsewhere, are distributed by the Kansas Department on Aging, KHPCO, LIFE Project staff, and Caring Communities.
- Kansas University Center on Aging, the Kansas Pain Initiative, Kansas University Medical Center, and numerous other LIFE Project Partners provide resources and presenters for Caring Communities.
- LIFE Project Partners work to create a variety of initiatives to improve pain management. The LIFE Project has:
 - Sponsored a pain management summit, in December 1999, gathering key health care professionals and public policy leaders in exploration of pain management policy and practice. LIFE Project Partners developed a common set of principles related to pain management and worked through media and professional organizations to create greater awareness and action around issues of pain management.
 - Brokered a Pain Management Protocol Project that was jointly developed by the Kansas Hospital Association, the Kansas Association of Homes and Services for the Aging, and the Kansas Health Care Association. This 15-month project, from June 2001 to September 2002, worked to identify and address systemic barriers to implementation of pain management procedures and protocols.
- Posted numerous pain management resources for consumers on the LIFE Project Web site at (www.LIFEProject.org)
- Sought and received data about pain management for Kansans nearing the end of life. The data, gathered by the Kansas Department of Health and Environment in the 2000 Behavioral Risk Factor Surveillance System, revealed that 86% of Kansans experience moderate to excruciating pain during the last 3 months of life.
- Utilized the data gathered by the Kansas Department of Health and Environment and sponsored a pain management summit in March 2001, gathering the licensing boards, key professional groups and public policy leaders. LIFE asked the Kansas Boards of Healing Arts, Nursing and Pharmacy to work together to issue joint pain management guidelines to further encourage Kansas healthcare professionals to respond fully to patients' pain. The LIFE Project remained actively engaged through the process of the development of the "Joint Policy Statement of the Boards of Healing Arts, Nursing and Pharmacy on the Use of Controlled Substances for the Treatment of Pain."⁵
- Hosted the announcement of the "Joint Policy Statement of the Kansas Boards of Healing Arts, Nursing, and Pharmacy on the Use of Controlled Substances for the Treatment of Pain" and worked to create media attention to the statement.
- Created and implemented a campaign, still continuing, for health care providers and the public, called "Every Kansan should expect good pain management." The LIFE Project has several public service announcements that are aired by members of the Kansas Association of Broadcasters. This ongoing campaign includes posters, a Kansas patient care bill of rights, media engagement, placemats, table tents, and other materials.
- LIFE has offered the American Medical Association's (AMA's) EPEC as an onsite and teleconference event, training 36 teams of physicians and nurses all across Kansas. LIFE has also cosponsored ELNEC and provided a host of presentations on end-of-life care and pain management across the state, gaining access to over 8000 Kansas healthcare professionals.
- With the assistance of the Kansas Humanities Council, a "Stories at Work" educational of-

- fering geared to impact perceptions and attitudes of health care providers related to end-of-life issues was developed. The Caring Communities identify health care professionals who might attend these various events and encourage participation.
- Key leaders of the Kansas PBS stations worked with the Caring Communities and other LIFE Partners to promote statewide viewership of the Bill Moyers *On Our Own Terms* series and to provide opportunities to engage people in discussion. The Kansas PBS stations assisted in promoting a consumer “call-in” number during and after each segment of the program. Additionally, they aired a “Statewide Town Hall Meeting” after the final segment of the show.
 - The Kansas State Library helped local libraries secure copies of the Moyers series making them accessible for further viewing and continue to provide access to end-of-life materials to citizens anywhere in the state. Numerous local libraries worked to create displays and to encourage Kansans to identify and address end-of-life issues. The LIFE Project created simple bookmarks that continue to be distributed in libraries, pharmacies, and other venues across the state.
 - Wichita State University assisted in creating public service announcements related to advance care planning, pain management and other end-of-life issues.
 - In 2001, a nationally distributed 15-part newspaper series on end-of-life care, “Finding Our Way,” was published. Caring Communities, trained by the editor of the *Lawrence Journal World*, worked for inclusion of the articles and for continuing press coverage on issues related to end of life care. Several papers wrote local stories to accompany the series. The circulation rate of these various papers, and the total numbers of articles, reached Kansans 1,176,000 times. The LIFE Project and Caring Communities, from 2000–2002, issued press releases and stories that were published by Kansas newspapers. The circulation rate of these various papers, and the total numbers of articles, reached Kansans 2,880,000 times. From 2000–2003, the Kansas LIFE Project and Caring Communities were able, by working with local newspapers, to reach Kansas readers a total of 4,056,000 times.
 - Kansas Senior Press Services provided, from 2000–2002, the opportunity for the LIFE Project to submit a monthly article for publication in weekly newspapers all across the state.
 - Kansas State University Research and Extension Services developed an end-of-life curriculum and, as the Moyers’ series was airing, 105 county extension agents were being trained using this curriculum. Their volunteer affiliate group prepared 3300 volunteers to teach the curriculum in thousands of small group settings across the state.
 - Shawnee Mission Medical Center developed basic materials and training for Caring Communities to engage faith communities.
- With the variety of initiatives and projects underway at any one time by the LIFE Project, its task groups and Caring Communities, communication, coordination, and networking are primary concerns. The statewide efforts are necessary for the local coalitions to create and sustain systemic and cultural change. The local coalitions are necessary for statewide planning and programs to be successfully implemented. The partnership between the two groups, which allows for shared expertise, resources and leadership, creates a structure that establishes and maintains strategies that are effective in improving end-of-life care in Kansas.

LESSONS LEARNED

Convene the right people to serve on coalitions. The Caring Community Councils that include active representatives from key organizations, providers, and/or entities are stronger.

Be inclusive. To truly be collaborative, competitive issues must be put aside. Engagement is strongest when all stakeholders and interested parties are invited and welcomed.

Leadership is key. Caring Communities that have a champion who is respected within the community are stronger.

Ongoing training, education, and engagement are important. Local coalitions learn, change and respond to varying needs. Acknowledging the strengths and challenges of each coalition is important to their success. The use of technology is vital to assisting local coalitions that are geographically distant.

The experts are the local leaders. State Partners can provide possible strategies and interventions, while the local coalitions have the best under-

standing of what is needed and will work in their communities.

Be clear about policies and ground rules. It is important to be clear about who may speak on behalf of the overall project. If the steering committee adopts policies related to statewide issues, all local coalitions need to abide by these policies.

Include representatives from the media. Media representatives including radio, television, press and public relations professionals are critical for reaching citizens.

Establish means for evaluation and product development. It is important to evaluate the project's efforts so that modifications for improvement can take place in an ongoing fashion.

Support coalitions' efforts to use and distribute materials. Community coalitions are effective in penetrating civic and faith-based groups, posting and distributing materials, identifying local needs, sharing key messages and actively engaging a variety of community leaders. When multiple related coalitions rely solely on volunteer action, staff support from the statewide effort is critical to continued success.

Listen and learn. Local leaders have perspectives that offer critical information to statewide efforts. Listening to these perspectives gives keys for action.

Celebrate success and good efforts. Celebrating successes keeps coalition members excited and interested.

CONCLUSION

Sustainable change on a statewide level is difficult. It requires commitment, energy, and a shared mission of many people and groups. It also takes hard work and adequate funding. The Kansas LIFE Project emerged at just the right time, when so many within the state were willing to share the mission of working together to help Kansans live with dignity, comfort, and peace as they near the end of their lives. Long-term sustainability, fiscally, will be challenging. While many of the LIFE Project Partners continue to support the efforts with gifts in-kind, the Project Partners do not provide substantive financial support. The creation, oversight, leadership, and

maintenance of such a broad-based partnership is supported by and depends on adequate staffing and funding for the LIFE Project. Grant funding still emerges as the most viable source of funding and the fiscal viability of the LIFE project will require continued success in securing that funding. The LIFE Project also now actively seeks personal and corporate contributions. Public policy to support quality care at the end of life is critical. Professional expertise in end-of-life care, long ignored in favor of rapid advances—in technology, therapies, medication, protocols and procedures—is receiving more attention. Consumer engagement, understanding and action are fundamental to lasting change. The LIFE Project Partners, Caring Communities and the citizens of Kansas, working together, are able to more fully address the needs of Kansans as they live near the end of life.

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