



LifeCircle™

SOUTH DAKOTA

Partners Improving End of Life Care

Executive Summary:

South Dakota's Dying to Know: End-of-Life Research 2004-2007

INTRODUCTION

This Executive Summary provides a synopsis of the full research report, *South Dakota's Dying to Know: End-of-Life Research 2004-2007*, available as a pdf file on our website:

<http://www.LifeCircleSD.org>

This research represents the first known vigorous multi-method exploration of public sentiment with respect to end-of-life care. The purpose of this research was to identify South Dakota citizens' knowledge, attitudes, and preferences at end of life. The combined results of this two-phase study are presented to educate the public, to engender further conversation, to inform public policy, and hopefully, to chart a future that will enhance quality of life at end of life for every South Dakotan.

As you read this document, please consider how it might inform your work and how it might generate conversations with your colleagues, your family, and with South Dakotans at end of life. Let us know your reactions to this monograph and how educational efforts might be framed to aid you and your colleagues in responding to issues at end of life.

STUDY DESIGN

Objectives:

1. Strengthen understanding of South Dakotans' knowledge, attitudes, and preferences at end of life
2. Learn what South Dakotans know about hospice and palliative care
3. Generate conversations among South Dakotans about end-of-life wishes
4. Provide data for policy makers, health care providers, clergy, and other professionals as they work to enhance quality of life at end of life

Research Questions:

1. What are South Dakota residents' attitudes toward death and dying?
2. How much advance planning and preparation have they done?
3. What do South Dakota citizens want at end of life?
4. What do they know about hospice?

Design: A *questionnaire* was sent to 10,204 randomly selected South Dakota households (with disproportionate sampling of Native American households), resulting in a 24.8% return rate. Open-ended *interviews* of about one hour were conducted with 36 respondents (a subset of the mail survey respondents). Data were analyzed by an interdisciplinary team, resulting in statistical findings from the survey and themes derived through narrative analysis of the interviews. Use of random sampling, the return rate, and the demographic profile of respondents indicates that the research findings are generalizable to the state of South Dakota.

Setting: South Dakota, 2004-2006

Participants: 2,533 South Dakotans over age 18 completed a 12-page questionnaire. Of those respondents, 36 visited one-on-one with a nurse researcher, discussing the death of a close other who had died in South Dakota in the previous five years. A full demographic profile of the two samples is available in the monograph.

RESULTS FROM THE QUESTIONNAIRES

1. What are South Dakotans' attitudes toward death and dying?

Eighty-nine percent of South Dakotans are comfortable talking about dying and 88% agreed that dying is an important part of life. Even so, they expressed fears and concerns about "dying well." They feared a long-term illness (64%), dying in pain (74%), or being a burden to loved ones (70%). Many indicated that living in great pain (63%), experiencing physical dependency (73%) or being unable to communicate (72%) would be "worse than death." Most respondents indicated it was "somewhat important" or "very important" to be free from pain (97%), have time to say goodbye (94%), and to be at spiritual peace (96%). Sixty-two percent said it would be "very important" to them to stay at home if terminally ill. Responses to other questions about pain suggest that misinformation about pain is prevalent and that education is needed to address common myths.

2. How much advance planning/preparation have South Dakotans done for end of life?

South Dakotans know what they want but have not necessarily taken actions to ensure that their wishes will be carried out: 53% had completed a financial last will and testament, 49% had filed an organ donation card, and 35% had completed some form of advance directive (e.g., living will or health care power of attorney). While six of ten had talked to their spouses (60%) or family (58%) about their

wishes at end of life, 15% had talked to no one. Further, the vast *minority* had discussed end-of-life wishes with their lawyer (16%), doctor (6%), or clergy person (4%).

3. What do South Dakota citizens want at end of life?

Most South Dakotans prefer that others (family 72%, health care providers 39% or clergy 38%) would initiate discussion about end of life. When asked about specific end-of-life medical technology, their preferences to allow for natural death were clear. Given the scenario of being terminally ill and unable to eat or drink, South Dakotans would not want artificial nutrition (75%), artificial hydration (64%), or machines that would prolong life (90%). Nearly one-fourth (23%) would want assistance with suicide if they were terminally ill.

4. What do South Dakotans know about hospice?

Fifty percent of respondents had heard “a little” or nothing about hospice. For those who were aware of hospice services, they typically had heard about hospice from someone who had used the hospice services (67%). Most (74%) said they would prefer hospice services at home.

5. Paradox and Change over Time

The findings from the survey suggest that there is a disconnect between what people want at end of life and what they do to ensure that those wishes are honored. A series of paradoxes were revealed. As an example, 15% had talked to no one about their end-of-life wishes; of those who have talked to no one about their preferences, 65% indicated that not being able to communicate their wishes would be worse than death.

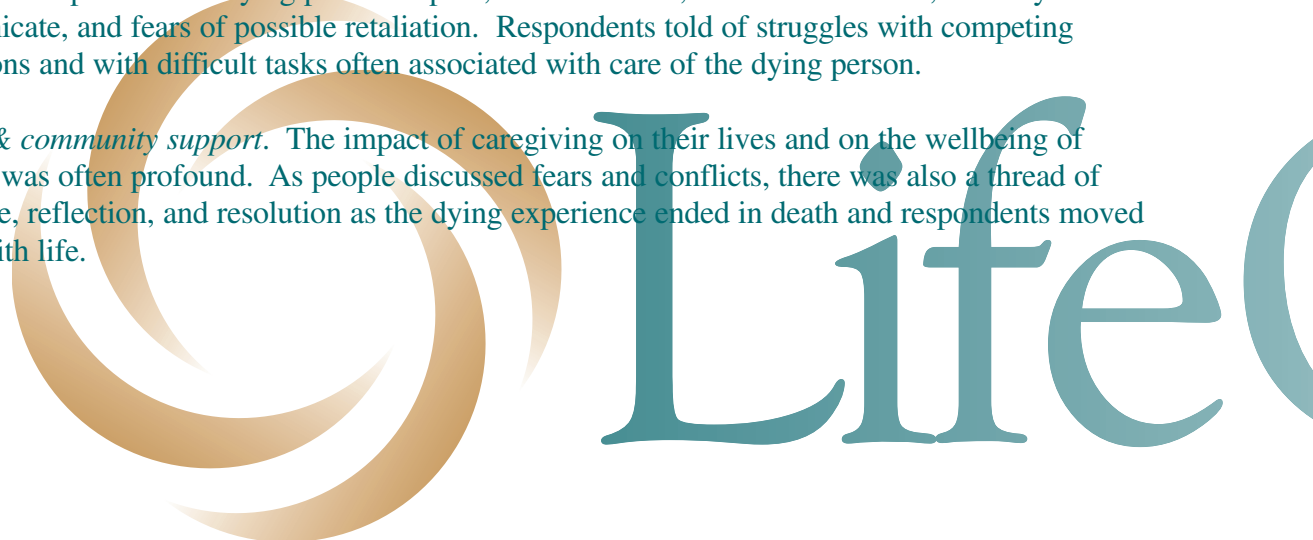
Changes in attitudes and behaviors over time were also examined by comparing a subset of the 2005 study (Sioux Falls respondents) to findings from a 2004 study of Sioux Falls residents. It appeared that over time, there was more talk, more action, and more awareness about end of life on the part of Sioux Falls residents. Views about end-of-life wishes became more polarized, with people falling out of the middle and gravitating toward more extreme views, indicating greater certainty about their preferences.

RESULTS FROM THE INTERVIEWS

Thirty-six tape-recorded interviews describing 47 deaths were transcribed, yielding over 1,000 pages of text. Broadly speaking, about 1/3 of the stories were positive, 1/3 contained both positive and negative elements, and 1/3 reflected negative experiences. *Ten key themes were identified:*

1. *Communication with the dying person and with health care providers.* A sense of knowing the person who was dying and having the opportunity for some kind of closure provided families and close others with comfort and helped them to make peace with their loss. Ways in which health care providers shared bad news, provided clear and intelligible information, conveyed openness to questions and sharing, and affirmed the importance of family and other relationships were extremely powerful.
2. *Dying trajectory and meaning of dying & death.* Respondents described a realization that the person would ultimately die. That realization ranged from gradual awareness to a dramatic cascade of deterioration. Elements that were central to the experience were the opportunity (and sometimes the burden) of bearing witness to suffering, participating in care, and being present at the time of death. They often recounted the manner in which they had attempted to fulfill the dying person’s wishes and to normalize the dying person’s day-to-day experience.

3. *Quality of care.* If care was viewed as high quality, family members and friends entrusted the dying person's care to professional caregivers. High quality care reflected a sense of genuine concern for the dying person's wellbeing, adequate pain management, and seamless coordination of care. The most powerful hallmarks of poor quality care were inattentiveness, lack of caring, inadequate pain control, racial discrimination, and failure to consider the dying person and his or her close others as unique human beings with their own valid life experiences and preferences.
4. *Importance of having an advance directive.* Most respondents confirmed the survey findings that health care providers should initiate conversations about end-of-life decision-making before dying becomes an imminent issue. Although most participants agreed that having an advance directive is important, many encountered barriers to acting on that belief. The major barriers were ambivalence about whom to designate as a proxy decision maker (durable power of attorney for health care), uncertainty about how to approach a conversation with family members, and reluctance on the part of close others to engage in the conversation.
5. *Decision-making.* The person who was dying and his or her close others were required to make choices related to treatment options, how much to engage directly in care of the dying person, and where that care should be provided. Participants were often torn between wanting to do the best thing for the dying person and being realistic about their own abilities and the safety of the dying person.
6. *Uncertainty.* Knowing versus not knowing what to expect was the most prominent description of uncertainty. For many participants, even after the death there were continuing doubts about caregiving decisions and whether they had done enough for the dying person.
7. *Access to care.* A primary barrier to access was the unavailability of services, such as hospice and home health care, particularly in more remote geographic locations. Other barriers included affordability of health care, lack of smooth transitions from one care setting to another, misinformation, and varied interpretations of policies and regulations.
8. *Coping with the loss.* Coping strategies included reminiscence, overt expression of grief, capturing memories in writings and scrapbooks, spiritual support, humor, and positive relationships with health care providers. All of them contributed to the survivors' abilities to cope with their loss.
9. *Fears and conflicts.* Respondents expressed fears of dying and dying alone, but often they coupled these revelations with acknowledgements of diminished fears after the death. Other fears pertained to undesirable aspects of the dying process—pain, loss of control, institutionalization, inability to communicate, and fears of possible retaliation. Respondents told of struggles with competing obligations and with difficult tasks often associated with care of the dying person.
10. *Family & community support.* The impact of caregiving on their lives and on the wellbeing of families was often profound. As people discussed fears and conflicts, there was also a thread of resilience, reflection, and resolution as the dying experience ended in death and respondents moved ahead with life.



Based on the interviews, two composite case studies were created to capture the experiences of many South Dakotans.

Kathy: A Positive Experience with Dying

My mother was 72 when she died—in my house, in that bedroom (pointing). She had had breast cancer earlier in her life, and we weren't really surprised when the cancer returned with a vengeance. Mom was living alone at the time, and wasn't real aware of services or agencies that could help her. I don't think she'd ever heard of hospice—Dad had dropped dead in the field several years ago, so this notion of a long-term illness was something new for our family. When we met with the doctor after the last surgery, we weren't sure what to think. Was there a chance that she would recover, or was this “the end?” We (my sisters and I) haven't always been great communicators—and this [her dying] was one of those issues that was especially easy to avoid. So, we fumbled our way along—trying to be optimistic and supportive, but never really giving Mom the chance to talk about her wishes at end of life. As Mom grew weaker, we tried to take turns coming around, doing the laundry and bringing in a hot meal. Over the next two months, we became closer as a family, calling each other regularly and seeing each other more than at holidays. With the hubbub of kids and spouses, holidays were times when it was usually hard to talk seriously; but now, there was time. One Saturday, we girls had come to have lunch with Mom, and she said, “When I'm gone, I want you each to have one of the antique plates on the dining room wall.” We were surprised that she was willing to talk about that [her dying]! And that was the point of change. More conversation opened up to more honest sharing of wishes, fears, and hopes. We got Mom enrolled in hospice but probably not as soon as we should have. She only lived 10 days with hospice care. The nurses and aides—and really the whole hospice team--treated our family with great respect and consideration and really seemed to care about Mom. They answered our questions, helped us know what to expect, and guided us in learning how to help with her care. They were always available for questions and problem solving; and they usually knew what we needed before we could ask. She was able to die peacefully at home, surrounded by all us kids.

Joan: A Negative Experience with Dying

My husband died of brain cancer in 2003. His early symptoms were so odd. For example, he tripped over his feet getting on an elevator—we didn't realize that he'd lost the lower portion of his vision. Anyway, we finally got him to a doctor who referred him to a cancer specialist. When the test results came back, the specialist told Ben he had a glioblastoma grade IV. Well, what the heck is that? We had to have a neighbor who was a nurse translate that for us—and it was not good news. We never got straight answers about what the prognosis was—the doctor was always using such big words; so maybe he did tell us, but we didn't realize it. I was scared stiff with the idea of caring for Ben at home as he died. I don't have any medical background, you know, and he was so unpredictable, sometimes belligerent and sometimes just listless and almost unresponsive. I was a little frightened of him and didn't know who to talk to about this—everyone at the clinic seemed so busy I didn't want to bother them. Our three kids are living on the coasts and having them come home seemed out of the question. They would email weekly, and that was good; but looking back, I needed more support from the family. Anyway, Ben finally was admitted to the ICU at the hospital. I don't think that anyone ever mentioned hospice to us—we didn't even know it existed in our region of the state—and if I did think about hospice, I thought it was for people in the hospital. I didn't realize that for all of those months of us struggling at home, we could have had help. What a rotten deal! Once he was in the hospital, I almost moved in there with him (especially once he was out of intensive care)—I just wasn't confident that he was getting adequate care at the end of his life. For example, they'd drop his tray off at noon and if I wasn't there to help cut his meat and encourage him, he'd have never eaten. He was a veteran and didn't want to complain about pain, but I could see it in him. I don't think I did very well by him in getting the doctors and nurses to treat his pain. He shouldn't have had to suffer so much. We didn't have a church home at the time, so I think he really struggled with what was “on the other side.” I think he could have had a much more peaceful death, and I would have appreciated a lot more help than I received.

WHAT HAVE WE LEARNED?

While most South Dakotans are comfortable talking about dying and death, it seems they would prefer that others *raise the issue*. Health care professionals and families clearly need to step over this hurdle, raising questions about end of life before a crisis and long before people become elderly.

South Dakotans have *strong values* that guide their views of end of life. They value self-determination, family, a relationship with the divine, and a respectful connection to their health care providers. The decisions they make about end of life are shaped by these values. Most South Dakotans acknowledge death as an important part of life and seem to abide by the notion of “*allowing natural death*”—rejecting artificial nutrition, artificial hydration, and machines that prolong dying. By and large, South Dakotans want to die at home, free of pain, surrounded by loved ones, with their affairs in order and differences and tensions settled (with family, finances, and with God).

Like most Americans, South Dakota citizens also have *misinformation about pain and medications*, and these false assumptions (e.g., medications can’t relieve pain, “good” patients don’t talk about pain, pain medications at end of life are addicting, it’s good to wait for more severe pain before taking prescribed medications, etc.) may adversely shape the dying experience.

The study also suggests *there are disconnects* between what South Dakotans want and what they have done to ensure those wishes are carried out by close others and health care providers. What we want will not necessarily happen unless we (a) share those wishes verbally and in writing with family, physician, and clergy, (b) complete an advance directive and will, and (c) make funeral plans known. The comparison of Sioux Falls residents’ answers in 2004 with responses in 2005 suggests that *conversation and education makes a difference*—in people’s attitudes, understanding, and actions.

RECOMMENDATIONS FROM SOUTH DAKOTA’S DYING TO KNOW

For Individuals

- Share your wishes with your loved ones.
- Communicate with key professionals (primary health care provider, lawyer, clergy).
- Complete an advance directive and share its contents with the above.
- Learn more about home health and hospice services available in your community.
- Invite those you love to engage in an end-of-life conversation to learn of their wishes.
- Do not presume you have a lifetime to complete these activities!
- If you know someone who is terminally ill, make contact through a visit, a phone call, or small gesture of concern.
- Recognize that there will be individual differences in how people want to approach their own dying, and respect those choices.

For Health Care Providers

- Initiate conversation about end-of-life wishes before a crisis.
- Discuss advance directives and help patients complete them.
- Clarify options for end-of-life care.
- Listen.
- Believe the patient’s account of discomfort and treat pain accordingly.
- Participate in educating the public.
- Advocate for people at end of life.

- Improve end-of-life health care policy.
- Educate yourself about services in your community and consider referrals.
- Recognize the importance of family and cultural differences.
- Examine your own attitudes and behaviors related to end of life.
- Be clear in communicating what is happening to people facing terminal illness.

For Lawyers and Clergy

- Ask people about their wishes for end-of-life care.
- Ask whether the individual has created documents and shared them with loved ones.
- Invite the end-of-life conversation when it may naturally fold into other conversations (e.g, writing a will or closing an estate or marriage preparation counseling).
- Realize that concerns about dying may be different than concerns about death and afterlife.
- Examine your own attitudes and behaviors related to end of life.

For Policy Makers

- Review *Last Acts* (2002) assessment of U.S. states' policies and legislation pertaining to end-of-life care (<http://www.lastacts.org>).
- Utilize *South Dakota's Dying to Know* data for conversations about end-of-life legislation.
- Ask for expert consultation in the areas of hospice and palliative care.

For Hospices

- Create a seamless mechanism for coordinating care with partner healthcare organizations.
- Recognize the importance of current users as messengers of the “hospice story.”
- Educate the community about advance directives and hospice services.

For Communities

- Create forums where conversations about end-of-life wishes may occur.
- Support local hospices and/or encourage their creation in localities lacking access.



CONCLUSION

South Dakota's Dying to Know has been an industrious attempt to systematically tap South Dakotans' knowledge, attitudes, and preferences about end-of-life care. Over 2,500 people volunteered to participate in this study--taking time, providing carefully considered answers, reflecting on recent deaths, and examining their wishes as they contemplated their own death and dying. This investment in the research enterprise was a gift to the state of South Dakota.

No doubt for many who participated in the research, completing the questionnaire and/or interview alone was catalyst for conversations with others. And we are hopeful that for those of you who read this, you, too, will venture into conversations with close others to describe your own wishes at end of life--and to invite descriptions of quality of life at end of life for them.

The findings from this study may provoke debate, action, and reconsideration of programs and policies. If it serves those purposes, it has been well worth the effort. Death comes to all of us. The challenge is how to embrace the dying process as part of life and make our wishes known to ensure quality in our living and the well-being of those we love.

ABOUT LIFECIRCLE SOUTH DAKOTA: PARTNERS IMPROVING END-OF-LIFE CARE:

Since 1999, LifeCircle South Dakota has engaged in dialogue about end-of-life care in South Dakota. The mission of LifeCircle South Dakota is to assure that the people of South Dakota receive the care they need to complete their lives and die peacefully, that their loved ones receive support, and that health care providers are skilled in palliative care. With assistance from the Sanford School of Medicine Department of Neurosciences, an array of projects have been undertaken: statewide research, an interdisciplinary palliative care educational seminar, community and professional education, and health policy consultation. An interdisciplinary and multi-institutional Advisory Committee oversees LifeCircle South Dakota, and maintains a website (www.LifeCircleSD.org):

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